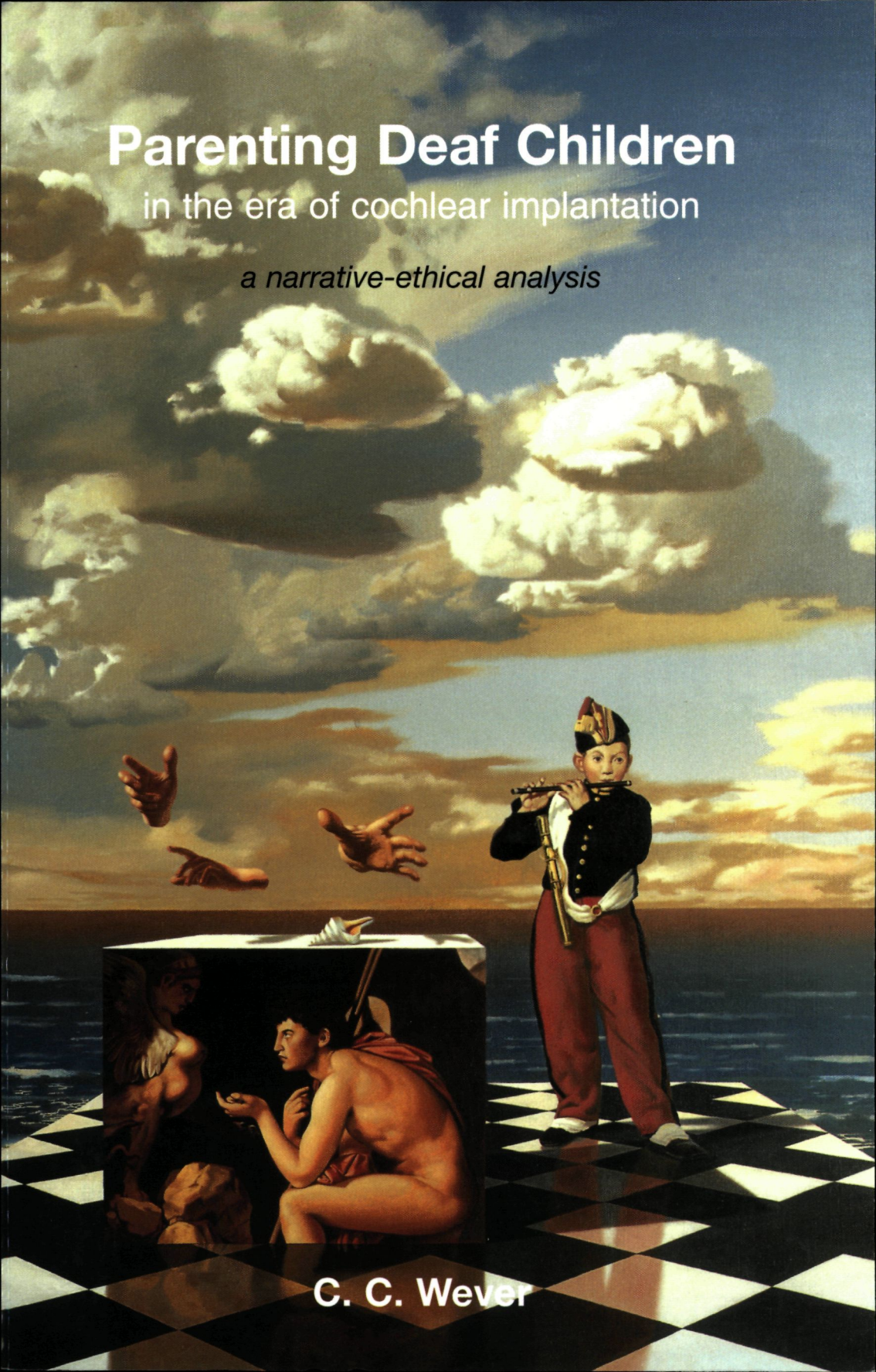
Parenting Deaf Children

in the era of cochlear implantation

a narrative-ethical analysis



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Parenting Deaf Children
in the era of cochlear implantation
A narrative-ethical analysis

Een wetenschappelijke proeve
op het gebied van
de Medische Wetenschappen

PROEFSCHRIFT

Ter verkrijging van de graad van doctor
aan de Katholieke Universiteit Nijmegen,
volgens besluit van het College van Decanen
in het openbaar te verdedigen
op dinsdag 11 juni 2002
des namiddags om 1.30 uur precies

Door

Casper Cándido (Capi) Wever
Geboren 27 april 1966
Te Nijmegen

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Voor Martine

Pa mi mayornan

CONTENTS

ACKNOWLEDGEMENTS

Over five years have past, since the first thought of writing a "philosophical" thesis on cochlear implantation was born It was a warm day in the late spring of 1996, when I made my way from Amsterdam to Nijmegen to meet Prof van den Broek I had just completed a study dealing with the experiences of people with a physical disability, and was ready to move on with my clinical career Yet it was not to be, or at least not as yet In a matter of about twenty minutes, Van den Broek ignited my curiosity and enthusiasm as he engagingly and empathetically drew the contours of what was to become the subject of this dissertation Cochlear implantation, a new medical technology aimed to improve sound awareness of profoundly deaf children, was stirring intense emotions in the adult Deaf community Deaf adults questioned the efficacy of the device and, moreover, depicted the paternalistic and prejudiced view on deafness that, they felt, underlies it I was instantly sold on the intriguing nature of this debate, quickly wrote a study proposal with Arko Oderwald, and eventually embarked on the study one year later

Little was I to know then where this study would lead me Writing this thesis proved to be a true "soul-searching" activity, that led me to the controversial field of minority rights and political-philosophy, to the caverns of my own prejudices on deafness and disability, and – having no children myself – to the "potential parent" inside of me It led me to a broad range of sciences and disciplines, which I did not master or did not master sufficiently at that time As such it inflamed a true reading-frenzy, which covered such areas as audiology, linguistics, psychology, political-philosophy, pedagogy, cultural anthropology and bioethics It also led to frequent and often lengthy debates with Deaf adults, parents of deaf children, a variety of professionals – both in The Netherlands as well as abroad - as well as with friends and colleagues who were willing to listen and think with me This study could simply not have been written without this wealthy input, and as such I am greatly indebted to all of those who supported me over the years – both materially as well as immaterially

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Finally I would want to thank all the parents that participated in this study and welcomed me into their homes to engage in long and emotionally intensive dialogue.

Nijmegen, April 22 2002

GLOSSARY

Adenotomy	Common ENT procedure in childhood Removal of nasal tonsil tissue
Amman	Sign language oriented school for the deaf in the western part of the Netherlands
ASL	American Sign Language
AZN	University Hospital Nijmegen The Netherlands' main center for pediatric cochlear implantation
BiBi	Bilingual Bicultural theory This theory aims to educate deaf children in both Sign language as well as the dominant spoken language, though the input of the latter is often limited to written language
CBS	Dutch Institute for Population Statistics
CI	Cochlear implant
CID	Central Institute for the Deaf, Saint Louis U S A Internationally renowned oral-oriented school for the deaf
dB	Decibel Unit expressing the intensity of sound
DC-ID	Deaf Culture Identity thesis This thesis claims that deaf children have the "right" to a Deaf culture identity The most foundational critique against pediatric cochlear implantation

deaf	Refers to the physiologic state of deafness or to deaf people who do not associate with Deaf culture.
Deaf	Refers to the cultural-linguistic unity that some deaf people form. Is capitalized much in the same way as "American" is.
Deaf culture	Refers to the cultural-linguistic unity that some deaf people form. Is capitalized much in the same way as "American culture" is.
Deaf culturalism	A political-ideological position that defends Deaf culture on foundational grounds.
Deaf-Deaf children	Deaf children with culturally Deaf parents.
Deaf-Deaf paradigm	Research paradigm that focuses on the state of deaf children of culturally Deaf parents.
deaf-hearing children	Deaf children with hearing parents.
deaf ecology	The social environment shaped by schools for the deaf. Includes teachers, social workers and other professionals as well as some deaf adults.
Essentialism	The foundational view that people have a nonnegotiable "core" that defines their being. A widely encountered position in minority advocacy. Characteristic of the DC-ID thesis and Deaf culturalism.
Ewing test	Population-based screening test for infant deafness.
Guyot	Sign language oriented school for the deaf in the northern Netherlands.

IvD	Institute for the Deaf Sint Michielsgestel. Famed for its oral-oriented curriculum.
Manualism	The ideological view that all deaf children ought to be schooled in Sign language primarily.
NGT	Dutch Sign Language
NIH	National Institutes of Health. Leading U.S. health authority.
NSDSK	Dutch Foundation for Deaf and Hard of Hearing Children. A leading Dutch diagnostic and research center.
Oralism	The ideological view that all deaf children ought to be schooled in spoken language primarily.
Serous otitis media	Common condition in childhood. The middle ear cavity fills with fluid, which causes mild hearing loss. Commonly remedied by placing ventilation tubes or "grommets" in the eardrum.
SES	Socio-Economic Status
Sign	Noun: short for Sign language. Capitalized much in the same way as "English" is.
sign	The verbal form of using Sign language
TC	Total communication

PREFACE

Hearing loss

Hearing is a capacity that is momentous in our lives Though most of us are likely to take it for granted, our ears organize the world around us, provide us the joy of music and mediate communication with others It is only when our hearing fails us that we become aware of the weight it really carries (Wentges 1993) As man grows older, hearing will deteriorate slowly but decisively Otolaryngologists, audiologists and speech therapists are quite familiar with the impact this can have on the lives of those affected Senior citizens see their social environment diminish through a process of *natural evolution* The added loss of the ability to communicate with intimate others often strikes hard and only adds to their sense of social isolation Though loss of hearing due to ageing, or presbycusis, is by far the most prevalent cause of moderate to severe hearing loss in the Western world, some people may suffer from varying degrees of hearing loss well before an advanced age is reached Chronic infections of the middle ear, noise trauma, infections of the meninges, "sudden deafness" and genetic hearing loss are some of the most common causes (Kunst 1999, Admiraal 2000)

To understand the mechanisms behind different forms of hearing loss, some background information must be provided The normal hearing process may be described as follows From the exterior to the interior, the outer ear metaphorically serves as the receiver of analogue sound waves The eardrum and middle ear ossicles function to amplify the signal and to facilitate an efficient transmission to the liquid medium of the inner ear The ossicles transmit sound vibrations to the small oval window, which in its turn will cause dynamic changes in the inner-ear fluid Fluid movements will stimulate the inner-ear hair cells, which results in an analogue-digital transformation The original analogue sound signal will continue its way as an electric signal, pursuing its way through the auditory nerve and central auditory pathways to finally reach the cortical auditory fields in the brain If hearing loss occurs through an obstruction of the analogue sound path, otolaryngologists speak of *conductive hearing loss* Two examples are obstruction of the external ear canal by a foreign body and labyrinthine disease such as otosclerosis If on the other hand, damage is inflicted on the inner ear the term is *sensorineural hearing loss* (SNHL) Some causes are presbycusis, autosomal dominantly or recessively inherited conditions affecting the inner ear structures and damage inflicted by infections such as meningitis Finally, hearing loss may also be due to damage to the central auditory pathways, termed cortical or central deafness

Hearing loss is classified by cause, type, and age of onset, but also by severity The table below summarizes two common classification systems

Table 1: Classification of hearing loss by severity

	RNID¶	ASA¶
Mild	25-39 dBHL†	41-55 dBHL†
Moderate	40-69	56-70
Severe	70-94	71-90
Profound	≥ 95	≥ 91

¶ RNID = Royal National Institute for Deaf people, ASA = Acoustic Society America
† average threshold in the better unaided ear across the speech frequencies (500-2000 Hz)

If hearing loss is of such severity that normal communication is hindered, otolaryngologists and audiologists will attempt to compensate this loss by amplification of the sound signal, usually through the prescription of a conventional hearing aid. When the loss of hearing exceeds about 60 dBHL however, even maximal amplification will typically not result in "normal" hearing. In general when hearing loss exceeds 60 dBHL, communicative problems increase exponentially. At first people characteristically report difficulty in engaging in conversations in which more than one speaker is involved or in situations with a relatively high noise content. At about 80 dBHL one will experience severe difficulty in recognition of monosyllable words, even under ideal circumstances, leading to significantly constrained communication skills. In the day-to-day practice of otolaryngology such communicative and social restraints are observed most commonly in presbycusis.

Profound hearing loss is a relatively rare condition. One source quotes 0.2 % (or about 30.000 people) as the prevalence of "total deafness" in The Netherlands (CBS 1990). This includes approximately 10.000 to 13.000 individuals who were either born with the condition or acquired it before spoken language was adequately developed, casu quo before the age of three – even though we mention that some prefer to use the age of two as a cut-off (de Graaf 1998; Paul 1993). The problems encountered as the result of acquired hearing loss compare relatively favorably to severe-profound hearing loss originating *before* language is established. The principal reason for this is that severe hearing loss preceding or coinciding with spoken language acquisition will have major consequences in terms of language development. Certainly, spoken language consists of more than auditory information alone. Yet if one has little or no access to the auditory cues of spoken language, the ability to master spoken language is severely inhibited or may even be entirely revoked. It is superfluous to say that the consequences of such an event are profound indeed: the inability to develop spoken language has severe social, cognitive and societal consequences. These "prelingual" deaf children, their care, their education, their social functioning and their future perspectives, have been the subject of intense debates for over 200 years (van den Broek 1999).

Educational controversy

Ever since deafness was recognized as a distinct cause of language impediment often comprising normal cognitive potential some 200 years ago, people have debated how its devastating effects could be overcome. After all, if the language impediment of deaf-mutes was not "primary" in terms of critically substandard neuro-cognitive potential but rather "secondary" to a more or less peripheral handicap, the appealing sense of challenge as well as moral duty arises almost instantly. Indeed, since the 18th century many efforts have been made to "unlock" the world of language to deaf people. Methods ranged from rigorous oral training with the aid of lip-reading, vibrotactile support and hearing aids to exclusively Sign language environments. The search for "the ideal method" still continues today and still succeeds to divide opinion. While it seems that, at least in theory, Sign language provides the best prospect for language development in general terms the main liability of this method is that it is likely to preclude spoken language development and as such the potential for social participation. Even though some linguists believe that proficiency in Sign language will facilitate the acquisition of the dominant spoken language, this assumption remains largely hypothetical and lacks convincing empirical evidence. Thus, the theorem that only the enhancement of hearing through technological support and in combination with explicit spoken language training can yield usable spoken language still stands firmly today, therefore maintaining the controversy.

Cochlear implants

The cochlear implant (CI) is a relatively new medical technology that aims to enhance the hearing level of post-lingually deaf individuals as well as children suffering from profound pre-lingual deafness. As such this technology has become involved in the debate over the education of deaf children. Deaf adults and hearing sympathizers of Deaf culture have charged fiercely at the introduction of implants in many Western countries with a wide range of arguments. Some of these arguments were aimed at implant teams, who were convicted of providing incomplete or misleading information about the potential of cochlear implants: contrary to what implant teams were saying, no benefits in terms of spoken language acquisition were to be expected. In addition, implant teams were saying nothing about the psycho-emotional impact of implantation and the ensuing spoken language training, which has been argued to be an unacceptable omission indeed. Other arguments however were aimed at the very principle of implantation, namely to encourage spoken language acquisition. These arguments are the most fundamental and represent a political or moral "counter-discourse". While only few have provided an encompassing critique on cochlear implantation and far but all arguments are sound, the general body of critique does reveal some issues of importance. Are implants indeed capable of assisting profoundly deaf children in acquiring usable spoken language skills? Do the procedure and the succeeding revalidation indeed yield psycho-emotional harm to

these children? If implants result in a spoken language advantage, yet on general linguistic or cognitive terms compare unfavorable to those enjoying an exclusive Sign language environment, which is to be preferred? If implants cause sub-optimal psycho-emotional well-being during childhood yet facilitate the ability to participate socially during adult life, should we consider the former an acceptable liability?

Parents of profoundly deaf children stand in the middle of these thorny questions, as it is ultimately they who decide to proceed with or withhold cochlear implantation. The decision they face is a special one for more than one reason. First and foremost because it is a "proxy" decision, implying that parents are in fact deciding for someone else. While it may be argued that such is inherent to all parenting decisions, it is particularly relevant to this issue. This is to say that although parents make many decisions for their youngsters all the time, the actual impact of these decisions on their child's future outlook is typically not particularly strong, barring extreme situations. From this perspective the case of cochlear implantation is unconventional. At least in theory the decision for or against an implant is a very significant decision indeed: it involves a medical intervention, possible significant impact on social-emotional functioning, language acquisition in general and spoken language acquisition specifically, cognitive functioning, educational outlook and societal and social opportunities. Only few conceivable parental decisions have such profound psychological and societal consequences. One may argue that pediatric oncology provides such a case. While it is undoubtedly true that decisions made in such a context are weighty and highly consequential, the discussion is by its very nature framed in a "life-death" rhetoric. In the case of cochlear implantation the argumentative pieces move within a much more intricate labyrinth, demanding more of parents' cognitive skills. This embedding of cochlear implantation makes the decision making process of parents a very interesting one indeed.

The aim of this thesis

This thesis will explore the modern day climate surrounding the education of profound pre-lingually deaf children. More specifically it will address the decision-making process parents face when their child is diagnosed as being deaf in a time when cochlear implantation is readily available to them. To achieve this we have collected empirical data through interviews with parents of both implanted as well as non-implanted deaf children. We will use these data to enhance our understanding of the pediatric cochlear implant debate. While much has been suggested about why and how parents choose for a cochlear implant, most of these suggestions have been hypothetical or based on casuistry. This study will therefore compensate this omission by scrupulously describing and analyzing the narratives of 23 interviewed parents of profoundly deaf children in the age of 3-15 years.

The debate surrounding cochlear implantation in pre-lingually deaf children seems to move back and forth between two global yet fundamental views on deafness One view, which is often labeled as the "medical view", perceives deafness as deviance primarily The other, which is often labeled as the "cultural view", perceives deafness as an existential trait Both views give rise to an elaborate network of values and rhetoric strategies We seek to clarify to what extent our empirical material fits or collides with this dualist scheme Are parents aware of the profound responsibility they face? How do they respond to this challenge? Are parents adequately informed about the details that form the landscape of their responsibility? Do they understand these details? How do they value these details and what factors influence this? How do they work things through to reach a final decision and which factors modify this process? How do they look back on that decision? While one objective of this thesis is to critically and meticulously shred light on these more or less procedural questions, the end of the scope is an evaluative ethical question indeed the main aim of this thesis is to provide an in depth view into the moral dimensions of the proxy-decision to proceed with or withhold cochlear implantation, a decision taken by parents What arguments are allowed into their deliberations, what are their goals, expectations, hopes and fears? How do specific ideas, goals, expectations, hopes and fears come to the forefront while others are toned-down? How do parents experience the responsibility they are expected to take and how certain are they about their decision? Rather than viewing cochlear implants as a detached issue or an a-historical technology, we located it in the center of the deaf educational controversy We argue that a true understanding of the significance of cochlear implants can be reached only if we come to understand deafness in its socio-historical dimension One of the premises of this study is that the decision parents make is a complex one, one that cannot be understood without understanding the socio-historical landscape of deafness as well as the specific relation they have vis-à-vis their child

The material presented in this thesis may serve several goals First and foremost it serves to provide insight into the landscape of deafness from a parental point of view Second, it facilitates our understanding of how complex decisions are made in a parental setting in general This information may assist us in expanding our understanding of the moral dimension of pediatric cochlear implantation It may however also provide a broader perspective on the issues parents face in making difficult proxy-decisions and how they go about reaching conclusions As such this thesis may be of interest to all of those involved with such decisions professionally From a practical point of view, it may assist those involved in the education of deaf children as well as those involved with cochlear implantation as a reference frame

Outline of the text

This text has been divided in three segments. Part one "Introduction and methodology" includes chapters one and two. Chapter 1 is an introductory chapter and outlines the history of deaf education and cochlear implantation, describes some aspects of being deaf in the 20th and 21st century and provides an overview of the controversy over pediatric cochlear implantation. Chapter 2 describes the methodology of this thesis. We made specific choices in the design of this study, choices which are not free of controversy. Without going too much into the detail of the "qualitative" versus "quantitative" debate, we will outline the debate and explain why this study utilizes a qualitative methodology. Part two "Empirical study" includes chapters 3 through 6 and consists of a chronological description of in-depth interviews with 23 parents of deaf children. Chapter 3 analyses parents' earliest experiences. These experiences are defined in time, as those occurring up to the moment of diagnosis. Chapter 4 proceeds with an inquiry into experiences immediately after the diagnosis is established and covers the language and school decisions that parents must take. Chapter 5 is set still later on the chronological axis, and analyzes the structure and influence of parents' new deaf school environment. Chapter 6 is specifically aimed at the cochlear implant decision, as well as experiences around the implant procedure and the revalidation period. We will also discuss implant results and how parents judge these results. Part three "Theoretical analysis" includes chapters 7 and 8. Chapter 7 represents a theoretical discussion of the vital concept "Deaf culture", and defines the moral space for the eighth and final chapter. Chapter 8 re-analyzes the cochlear implant debate from a pragmatic ethical perspective and will focus on the concept of best-interest.

PART I

CHAPTER 1 - INTRODUCTION

INTRODUCTION

If one aims to clarify and understand the decisions that parents of a deaf child face as we described in the introduction of this thesis, one will need to have an understanding of the contemporary climate or "landscape" surrounding the education of deaf youngsters. The physiognomy of this landscape is grounded in both historical as well as modern narratives. Perhaps more strongly so than most educational discourses, the deaf educational debate and therefore the cochlear implant debate has strong historical roots. The deaf educational debate has a striking sense of historical awareness and is involved in an ongoing dialogue with history. It is therefore indispensable to be acquainted with this history. In addition, the deaf educational debate is strongly intertwined with contemporary scientific as well as political and moral insights. It is for example close to impossible or at least pointless to discuss the well-being of deaf children without referring to modern linguistic and psychological theory. It is equally pointless to discuss the issue without making reference to pedagogical theory and the minority rights discourse. Most all actors, be it theorists, Deaf adults, deaf teachers or parents of deaf infants, speak this language of history, science and morality: hence, to understand them entails an understanding of the structure of their language. In this chapter we will provide an outline of this language, by focussing on the history of deaf education, on recent scientific insights into deafness, on the development of cochlear implants and on the controversy surrounding their introduction.

HISTORICAL OVERVIEW OF DEAF EDUCATION

Introduction

Much has been written about the (lack of) objectivity of historical reviews. It appears that any review will be a construction by emphasizing some developments while minimizing others We too will structure this review. We will do this in such a way so to illuminate the more profound moral clash that underlies the deaf education debate and which is postulated to be of much value in understanding the cochlear implant controversy We have relied on one landmark publication. Lane's brilliant epos titled "When the mind hears: a history on the deaf" (Lane 1984) Even though Lane's work may indeed be argued to represent a "pious biography", it does provide "the facts" abundantly to the discriminating reader (Wrigley 1996) Another work of importance is Tellings' "The two hundred years' war in deaf education" (Tellings 1995)

Manualism versus Oralism

Deaf education represents a field full of controversy expanding over many decades The controversy tends to oscillate between two educational and ideological views, commonly labelled "manualism" and "oralism" The first roughly represents the aim to educate deaf children in the regional Sign language primarily, the second to teach them the principal spoken language Oralism does not generally value spoken language as a goal in itself, but rather the enhanced perspective that such mastery is presumed to yield in terms of integration in mainstream society as well as the enhanced opportunities for individual development and autonomy (Tellings 1995) Additional focal points for oralism have been the issue of literacy and "free choice" of language and socio-cultural environment Ling formulates the benefits of oralism as follows

> The greatest opportunities for communicative interchange, personal-social growth and independence, educational achievement, and advancement in employment are open to those who have the best command of spoken language (Ling 1989)

Advocacy of manualism on the other hand, is somewhat more complex to capture because of the heterogeneity of the arguments involved. One key issue is the issue of cognitive and language development, which are intricately related Many advocates of manualism feel that it is not spoken or written language that must be the key aim of deaf education, but rather general cognitive and language proficiency. Since learning oral language represents a major challenge for deaf children, this must limit their developmental roof Sign language on the other hand has no such restrictions and therefore represents the optimal medium for deaf individuals Another argument that is voiced by many advocates of manual instruction pertains to the socio-emotional

development of deaf children A low threshold language of instruction, an environment in which deafness is not synonymous with social stigma and the availability of adult role models are thought to be paramount for a healthy socio-emotional development Contrary to oral-mainstream strategies, a sign/deaf-culture strategy is believed to yield Deaf people who are "proud" rather than ashamed of their deafness (Tellings 1995) It therefore appears that advocacy of Sign language is often not so much a primary preference, but rather based on the assumption that the goals of oralism are unattainable and yield unacceptable (socio-emotional-) moral liabilities (Wever 1998) While oralists do not deny these liabilities per se, they worry that an exclusive Sign language approach to deaf education will preclude spoken language development Jensema reported that deaf children are inclined to develop a single communication mode (Jensema 1978) Arguments by those in favor of oral instruction pertaining to the "unacceptable" restrictions of manual instruction on oral language proficiency and integration capabilities, have been rejected by manualists through two main avenues First, it has been argued that Sign language instruction *facilitates* rather than obstructs the acquisition of spoken language This argument has been founded in linguistic (bilingual) theory as well as some empirical observations of Deaf children of Deaf parents (Deaf-Deaf paradigm) Nonetheless most sign and bilingual-bicultural programs, such as those in Sweden, aim to equip deaf students with only minimal spoken language skills, thereby not revoking the critique of oralism entirely (Tellings 1995) Second, it has been argued that restrictions of spoken language and mainstreaming capabilities are "acceptable" liabilities indeed, an argument which is typically founded on specific political-philosophical premises which intricately link deaf children to Deaf culture, the culture they "belong" to Indeed, as Tellings also argues, the controversy between oralism and manualism is founded at least in part in the broader political-philosophical debate between liberals and communitarians, something we will expand on in chapters 7 and 8 of this thesis (Tellings 1995) While the former view stands open to an individual approach to deaf education, the latter is more likely to promote a single mould for all deaf children, an implication which has been criticized (Wever 1998, Stewart 1992)

Even prominent Deaf culture spokesperson Lane is not always consistent in his convictions While his opposition to oralism seems rather foundational in some publications, in others he appears more strongly preoccupied with the liabilities of mainstreaming strategies (Lane 1992) What seems to concern Lane is the semiotic message of inadequacy, which is inherently transferred when a deaf child is implanted or when a deaf child is mainstreamed More specifically, Lane appears to anticipate on and worry over the considerable negative impact this may have on a deaf child's self-image or self-esteem The next excerpt from his chapter "The role of the oppressed" reveals this standpoint

> If the child is the object of extensive oral drills, which are painful and frustrating, the concept emerges Something is wrong with me When he goes off to a school or program

> for deaf children, where the urgency of understanding lip movements is greater than ever, what is wrong becomes localized (Lane 1992, 93)

Pollard, a psychologist and well-known criticaster of cochlear implantation, shares this psychological concern with Lane:

> Critics from the Deaf community note that the implant may impair a child's self-esteem, their body image, or the quality of the child and family's acceptance of the hearing loss. These points are well taken. The device itself becomes an integral part of the child's body, something that sets them apart from others, including deaf peers. Implantation is a deeply personal event, one that the child must reinterpret at each stage of their social and sexual development. (Pollard 1993b)

Thus it appears that Lane and Pollard's opposition is not so much founded in the notion of integration as a moral concept, but rather in what they perceive to be unacceptable emotional liabilities of such a strategy. In doing so, Lane and Pollard place their opposition in the context of a large body of self-esteem research that has been produced over the last four decades or so.

As stated in the previous section, the manualism-oralism debate still continues today. Cochlear implantation has been enveloped into this broader debate, which makes a review of the history of deaf education meaningful, particularly in the light of the dialogue between these two outermost positions. In the next section we will provide an outline of this tempestuous history.

Phases in deaf education history

Kuhn's paradigm theory shreds new light on the history of knowledge (Kuhn 1969). Rather than conceiving of knowledge as an ever growing cognitive body, Kuhn describes how the growth of knowledge follows a phase-like path, strongly influenced by social factors rather than scientific inquisitiveness per se. Kuhn's theory leaves in the middle "who is right" but is rather interested in who has the social claim on truth during a specific historical period. If one view on truth or "paradigm" dominates during a specific historical period, this will consequently lead to an expansion of the body of knowledge within that specific paradigm as well as an expansion of the sphere of social influence of representatives of that paradigm. Kuhn labels such events as periods of "normal science". If on the other hand a competing view arises which manages to establish socio-cultural influence, scientific inquisitiveness will likely soar in the struggle for dominance. Such events are labelled as periods of "revolutionary science". As we mentioned in the introduction of this chapter, deaf educational history has been characterized by two leading views, oralism and manualism. Notwithstanding some evidence of hybrid views such as Total Communication (TC) in the 1970s and Bilingualism in the 1980s and 1990s, it appears that the competition between these two views has determined the path

of deaf educational history in a significant way We have ordered deaf educational history in five distinct phases In each of these the social, scientific and political relationship between the oralist and manualist paradigm has been the main orientation point

Premodern period (before ~ 1750)
- Key Figures Bonet, Ponce de Leon, Amman
- Knowledge identification of deafness as a distinctive cause of under-development
- Practice first educational experiments

Modern period (1750 - 1880)
- Key figures De L'Epee, Pereire, Heinicke, Thomas Gallaudet, Braidwood
- Knowledge competing educational paradigms
- Practice establishment of deaf education

Post-Milan period (1880 - 1960)
- Key figures Bell, Edward Miner Gallaudet, Van Uden
- Key events Milan Conference
- Knowledge oral paradigm
- Practice dominance of oral method

Linguistic period (1960-1990)
- Key figures Stokoe, Bellugi, Meadow, Tervoort
- Key events 1 US Bilingual Education Act (1968)
  2 US Public Law 94-142 (1975) supporting mainstreaming
- Knowledge sign language research, leading to competing paradigms
- Practice rapid penetration of sign language in deaf education

Disability rights period (1990-2002)
- Key figures Lane, Padden, Wrigley
- Key events 1 US ADA (1990) provides more support for mainstreaming
  2 Gallaudet uproar (1988)
- Knowledge 1 Disability rights legislation requiring establishment of Identity and Culture
  2 Bilingualism
  3 Cochlear implants
- Practice 1 Establishment of sign language in deaf education
  2 Introduction of the concept of bilingualism in deaf education
  3 Establishment of cochlear implantation

Pre-modern period

Few comprehensive studies have been published which focus on the state of deaf people prior to the 16th century or so Nonetheless assumptions about this state are encountered quite frequently Speaking about disability in general, Winzer labels the situation prior to the eighteenth century as one of "dread and despair" (Winzer 1993) Jankowski states that prior to the late 18th century, deaf people were not perceived as competent citizens, were not considered people at law and deafness itself was not well understood nor distinguished from other states of severe under-development, most noteworthy mental retardation (Jankowski 1997, Lane 1984) Hence, the deaf-dumb are said to have been viewed as social outcasts and were considered uneducable Their faith was gloomy, in particular since adequate recognition of deafness was lacking which regularly resulted in institutionalisation in asylums for the disturbed (van den Broek 1999) Lane also expresses a similar view as he speaks of "the deplorable state to which the deaf-dumb were reduced" (Lane 1984) He continues

> Those who were deaf at birth or deafened before learning French were hidden away out of shame, or abandoned by the roadside like the count of Solar, or secreted in some institution, or simply to vegetate (Lane 1984, 47)

Considerably more is known about the state of deaf education in the late 16^{th} and 17^{th} century In very general terms, it appears that the roots of deaf education are to be found in this period in part due to the fact that deafness was recognized as a distinctive cause of under-development Though attempts were made to teach the deaf (spoken) language, such attempts were mostly restricted to individuals of fortunate ancestry and represented small-scale efforts (Lane 1984) The most renowned example is perhaps the story of Pedro Ponce de Leon (1520-1584), arguably the first person to devote him self to teaching the deaf to speak (Admiraal 2000) Ponce de Leon was hired to teach two deaf descendants of the noble Spanish Velasco family to speak The two were the trust holders of the family's estate In sixteenth century Spain those unable to speak were not considered persons at law and were therefore legally denied the right to fulfil the position of heir, which in the case of the Velasco family would have implied that they would have seen their fortune lost Countryman Martin Pablo Bonnet would continue Ponce de Leon's work in the 17th century (Admiraal 2000) The late 16th and 17th century also marked the publication of some important volumes on the education of the deaf by Bonet in 1620, Wallis in 1653 and Amman in 1692 As may be illustrated by the title of Amman's work "Surdus Loquens" ("Talking deaf man"), the focus was mainly on methods to teach the deaf spoken language, albeit with the assistance of manual codes (mostly finger spelling) Lane presents Ponce de Leon, Bonnet and Amman as the founding fathers of oral education to the deaf (Lane 1984)

The Modern period

Without question the 18th-19th century is an important period in the history of deaf education. While there had been some interest in deaf education prior to this date, it was not until the late 1700s that deaf education became widespread and more institutionalized if you will. It appears that this trend should not be perceived as independent but rather related to the socio-cultural climate of the time: towards the end of the 18th century many schools for the deaf, as well as asylums for other disabilities, were founded throughout the Western world. Early on two distinct and rather conflicting educational methods arose in Germany (oral) and France (manual). The prestige of the traditions that came into being in these two countries was so grand that even today many western countries write their deaf histories in terms of their relation to either the "German" or the "French" tradition. The most famous of 18th century clashes over methodology occurred between the heads of two schools for the deaf in Bordeaux and Paris respectively: Pereire and De L'Epee.

Catholic abbey Charles Michel De L'Epee (1712-1798) was the director of the first private school for the deaf in Paris, founded in the 1760s. De L'Epee had a particular interest in the manual language that deaf adults used to communicate with each other in Paris, accumulating in his much acclaimed 1776 publication "Institution des sourds et muets par la voie des signes methodiques" (De L'Epee 1776). De L'Epee is commonly represented as a compassionate advocate of Sign language. Sign language was used by the Deaf in Paris and elsewhere long before de L'Epee established his school yet neither de L'Epee nor his successor Sicard were *genuinely* interested in the sign used by Deaf people themselves (Wrigley 1996). De L'Epee's interest in manual languages appeared to be driven primarily by his demand for a tool to teach the deaf spoken language as well as his need for a language of instruction (Wrigley 1996; Lane 1984). This aim appeared to be stimulated by the desire to reveal the gospel to the deaf (Wrigley 1996; Tellings 1995; Admiraal 2000).

> I am prohibited from leading the hearing to know God; I will lead the deaf to know Him. I am prohibited from teaching those who speak to sing his praises, I will teach the deaf to sign them. (Lane 1984, 54)

De L'Epee perceived of spoken language in itself as an inefficient language of instruction compared to the "methodical sign" that he developed and which comprised a transformation of Sign language to fit the structure of spoken French, not unlike the theorem of manually coded sign or Total Communication that would surface in the final quarter of the twentieth century. Notwithstanding their interest in the manual language of the deaf, both De L'Epee and Sicard were publicly advocating their endeavor based on the progress made in terms of written and spoken language. As Lane argues, reading and speaking deaf-mutes were considered no less than a miracle at that time. Sicard was particularly famous for his public demonstrations.

> I will now take you to the top. I will thank any gentleman for a book or newspaper; we will exercise the talents of this young man, Massieu. Someone in the audience furnished the day's Gazette. The abbé signalled me [Laurent Clerc - ccw] to come onstage and sign the text of an advertisement.
> "Clerc will dictate the passage to Massieu, who will show you that he is able not merely to comprehend the ideas, but to repeat the exact words appearing in the paper."
> I then communicated the passage in manual French while Massieu wrote it on the blackboard.[...]
> The audience was obviously pleased and impressed.
> "Ask him any question," Sicard continued, "and I engage that his answer shall be prompt, clear and correct." (Lane 1984, 35)

Notwithstanding, compared to Pereire, both De L'Epee and Sicard did prioritize the value of general language skills more strongly so than oral language skills (Tellings 1995).

> As charmed as Epée was to hear his pupils speak, he would never allow French - spoken, fingerspelled, or written - to become the vehicle for their basic instruction. That would be to rest all on the very faculty the deaf lack, to take one of the ends of instruction as its means. When this course is followed, it takes so long to build the language skills in French that education is postponed indefinitely. (Lane 1984, 97-98)

De L'Epee's school attracted much attention of educators worldwide. Dutchman Henri Daniel Guyot for example was inspired by De L'Epee's school when he founded the first school for the deaf in the Netherlands in 1790 (Admiraal 2000). De L'Epee's institute also influenced early deaf education in The United States. Thomas Gallaudet visited the Paris school in 1815 and was so much fascinated with what he encountered that he returned to his country with one of the institute's most prominent deaf teachers, Laurent Clerc, with whom he founded the first American school for the deaf in Hartford, Connecticut (1817).

Jacobo Pereire (1715-1780), the director of one of the first French schools for the deaf, was inspired by the work of advocates of the oral methodology such as Bonet and Amman (Lane 1984). Though Pereire did use finger spelling, this was instrumental to his ultimate goal of teaching the deaf spoken language. During his life Pereire was involved in fierce methodological rhetoric and rivalry with De L'Epee. In the end De l'Epee "triumphed" as Louis XVI decided to withdraw his initial subsidiary from Pereire's school and grant it to De l'Epee instead. Lane comments:

> Thus, the language of the deaf emerged victorious from its first major battle in the new era brought about by the abbé de l'Epee. Pereire stopped teaching speech, his pupils stopped using it, and when they died nothing was left behind - nothing, that is, except a moral lesson that most continue to ignore (Lane 1984, 100).

Even though this is frequently suggested, Sign language was *not* a global phenomenon during the 18th and 19th century. While Sign language may have thrived in

France and The United States, in many other countries, such as Italy, Austria, Switzerland, The Netherlands, Belgium and Norway, oralism blossomed (Lane 1984). Followers of Amman such as Heinicke in Germany, and Wallis in the UK succeeded in getting a strong grip on deaf education at about the same time as l'Epee won his battle against Pereire. Heinicke founded his school for the deaf in Leipzig in 1778 and many schools for the deaf would follow in his tradition (Lane 1984). Heinicke is viewed as the founding father of the German school, which remained a source of influence for oral programs. Heinicke and De L'Epee were well aware of each other's work as they exchanged their views through correspondence. The legacy of oral education in the British Isles was deputized by Thomas Braidwood, who founded the Edinburgh school, one of the most renowned oral schools in Europe, which was to become an inspiration for many other schools in the UK as well as the United States (Lane 1984). It is this school that Thomas Gallaudet visited first to learn about deaf education. The school's refusal to cooperate unless Gallaudet committed himself to years of apprenticeship eventually drew Gallaudet to L'Epee's school in Paris. It should be mentioned however that even though sign based instruction has dominated in American schools for the deaf, interest in the oral method did not cease altogether during this period, as evidenced by the opening of the Heinicke-based Clarke School for the Deaf in Northampton (Massachusetts) in 1867.

How did this sudden interest in the education of the deaf come about? Lane localizes the interest in the ideology of the 18th century Enlightenment. What this means is not entirely clear, after all the Enlightenment is a generic term covering a wide range of developments. It appears that Lane at least in part utilizes the sense of "social justice" which is typically connoted to the Enlightenment. In social-political terms, the Enlightenment is perceived as the cradle of modern democracy, a period during which class-ruled society came to its end. It may therefore be suggested that the interest in the deaf originated in the social-political ideology of the Enlightenment, in which "social oppression" was a central issue. In philosophical terms, the Enlightenment often denotes a new epistemology based on reason and empiricism rather than tradition, authority, dogmatism and superstition. The work of Diderot illustrates how the social-political and philosophical spheres are interrelated: Diderot aspired to assemble an "encyclopaedia of knowledge" which he planned to distribute amongst the people, which would as a result liberate them from the authoritarian grip of the church, monarchism and metaphysics (Diderot 1780). Hence the Enlightenment entailed a departure from authoritarian "agencies of truth" and sought a democratic alternative in reason and empiricism, much encouraged by the spurt of rational science in the 18th century. As such it is no surprise that many Enlightenment thinkers struggled with the issue of the relation between reason and truth in search for a new foundation for knowledge. Yet it was not so much the hope to find such a foundation which stimulated philosophy, but much more so the desire to understand how truth comes into place, to provide insight into the organisation structure of knowledge. As would become the case for many twentieth century thinkers such as Wittgenstein, the role of language was much under investigation (Wittgenstein 1963). In many ways language is tradition and as such could potentially compromise the search for

a new foundation of truth "Can we perceive without language?" and "Can we think outside of language?" were just some of the fundamental questions that were addressed As a result of the spirit of their times, nineteenth century scientists and their twentieth century contemporaries were highly interested in case studies of individuals who represented an "altered language experience" If indeed language was an important agent of thought and if thought was the medium in which truth and morality are encrypted, how did thought and morality develop in those lacking a (conventional) language experience, such as the deaf and wild children? From this perspective it comes as no surprise that Pereire, de L'Epee and Sicard were drawing abundant attention from their contemporary social and intellectual elite Pereire was for example befriended with Jean-Jacques Rousseau Just some celebrities who visited de L'Epee's school were Bonnot de Condillac and John Quincy Adams

The 19th century may be perceived as a turning point from another perspective It appears that De L'Epee's school set the standard for the relation between society, the family and the deaf The French National Assembly sponsored de L'Epee's school with the argument that "The deaf-mutes who were adopted children of the abbé de L'Epee will thus be those of the Nation, and the Nation will do for them, for reason of justice and social welfare, what the abbé de L'Epee had been inspired to do" (Lane 1984) The education of deaf children would since then be considered a *public responsibility* which is illustrated by the establishment of state sponsored boarding schools for the deaf world wide.

The post-Milan period

Since the International Congress on Education of the Deaf, held in Milan on September 6th 1880, oralism became the dominant method in deaf education. Not much is known about the reasons behind this shift, though it seems that politics were of greater importance than new scientific facts With a vote of 158 to 6, educators who met at the Milan conference set the course for deaf education for almost a century In the United States the opening of the St. Louis based Central Institute for the Deaf (CID) in 1914 was a landmark in terms of the oral years that were to follow Many deaf schools eventually adopted the oral method, though the degree to which they did varied somewhat. In the Netherlands for example, hybrid methods in which manual language ("Dutch in sign", developed by the Institute founder Martinus van Beek) remained a factor were still dominant at the Sint Michielsgestel Institute for the Deaf up to 1906 (Admiraal 2000)

In the United States Alexander Graham Bell is often identified with this period of oral influence Bell, son of a deaf mother who had mastered spoken language, was a strong advocate of the oral method and vindicated sign based instruction of generating an isolated community of deaf people (Lane 1984) Enforcing his views against such a community, Bell opposed deaf intermarriage and even advocated sterilisation of young

deaf women, which resulted in the fact that many today associate his views with eugenics. During his life, Bell was involved in a fierce rhetoric with the main advocate of the manual method at that time, Edward Miner Gallaudet, son of Thomas Gallaudet (Van den Broek 1999; Winefield 1997). Edward Miner Gallaudet was also the son of a deaf mother, yet she communicated in Sign primarily (Broesterhuizen 1992). The rhetoric extended well beyond the language issue in itself as Gallaudet and Bell also disagreed in terms of their social and moral views on deafness. Bell was a strong advocate of social integration and as such opposed any system that would add to the segregation of deaf people while Gallaudet viewed these goals with little regard. The animosity between the two gentlemen peaked at the 1890 International Congress of Teachers of the Deaf. At the end Bell arose as the "winner" as the congress voted to maintain the position of the Milan Congress.

In the Netherlands, Van Uden embodies the views of this period. Van Uden spent most of his professional career at the Institute for the Deaf in Sint Michielsgestel, which has as such become strongly associated with the oral method. Like many other deaf educators of his time, Van Uden felt that the low threshold of Sign language would draw attention away from spoken language, ultimately resulting in a failure to develop spoken language up to potential (van Uden 1970). Such a failure, he believed, was undesirable since it would predestine deaf people to a segregated life, a life in the deaf "ghetto". Today some authors are still worried over this issue in the context of the rise of bilingual programs: Stuckless (1991, in: Tellings 1995) and more recently deaf lawyer Tucker (1998) have warned that the bilingual approach may end up in a monolingual sign system instead. Van Uden also upheld the idea that Sign language was to be perceived as a "depicting language, keeping thinking slow, much to concrete, and too broken in pieces" well after the studies by Stokoe, Bellugi and others had proven this wrong (Van Uden 1970). This latter position resulted in a growing critique, mainly by new generations of Sign language linguists.

The linguistic period

It took over 80 years of predominantly oral education for manual language to find its way back into the limelight, triggered by the Stokoe's "Sign Language Structure", published in 1960 (Stokoe 1960). Stokoe's groundbreaking message was that Sign languages represented *true languages* rather than being a rudimentary form of communication as Van Uden and others had claimed. This finding imploded the argument that the choice between spoken and Sign language was not a reasonable choice really since the latter was an inferior language. Other persons of importance were linguist Bellugi and psychologist Meadow, both of whom performed groundbreaking research in the field of Sign language and deaf psychology (Bellugi 1974; Meadow 1967). In the Netherlands Sign language research was instigated by linguist Tervoort. Tervoort started his career at the Sint Michielsgestel Institute for the Deaf, but left the institute for an appointment at the

University of Amsterdam in the 1970s. By then his disagreement with Van Uden had grown to considerable proportions, a disagreement which would continue after his departure from the institute (Van Uden 1984; Tervoort 1986). In the wake of Tervoort an entire generation of Sign language linguists sprouted who were to carry Sign language to its definite breakthrough.

The winds of change that Stokoe's report brought about allowed the established oral paradigm to be investigated in terms of its merits and liabilities. If an exclusively oral environment was a prerequisite to satisfy the goal of spoken language and social integration as Bell and others had argued, how well did it actually succeed? In the years that followed, the balance of 80 years of oral education was slowly made, a balance which proved disappointing to say the least (Tellings 1995; Broesterhuizen 1992): only few profoundly deaf individuals were "successful" ergo only few actually managed to master spoken language so to find their way to increased opportunities in hearing society. As observed cross-sectionally in 1986 by Schildroth and Karchmer, most hearing-impaired adolescents' reading skills remain at the level of a hearing 3rd grader (Schildroth 1986). Even though the factual situation may have been somewhat less gloomy, since a cross-sectional sample inherently clusters different educational models and educational quality and additionally loses those successful at mainstreaming in the follow-up, the key message stood firmly at the time (Geers 1989). Advocates of manual instruction interpreted these results as proof of the bankruptcy of the oral method and as a strong indication that alternative modes of education needed to be developed. The main alternative direction was believed to be Sign language.

In the 1960s a series of studies concerning Deaf children of Deaf parents gave rise to what is commonly referred to as the Deaf-Deaf paradigm. The Deaf-Deaf paradigm was perceived as an adequate model to estimate the *potential* of the Sign language alternative for deaf children of hearing parents. Several early studies revealed that Deaf children of Deaf parents outperformed deaf children of hearing parents in cognitive terms (Balow 1975; Quigley 1961; Stuckless 1966; Paul 1993). Advocates of the oral method were sceptic about these findings. What these studies failed to consider is that deaf children of hearing parents are more at risk for multiple handicaps. In addition the typical cross-sectional approach was argued to be fallible since it implies that one will lose mainstreamed oral children to follow-up, in addition to failing to measure possible longitudinal development differences.

The 1960s also gave rise to a growing interest in the psycho-emotional functioning of deaf children (Meadow 1968c; Altshuler 1974; Broesterhuizen 1992). Findings of sub-optimal psycho-emotional functioning of deaf people had been reported well before the 1960s however: several studies reported unusually high scores of neuroticism (Pintner 1933) and unadaptive behavior (Brunschwig 1936). Yet it appears that up to the 1960s these findings were considered more or less *intrinsic* to deafness, ingredients of a "deaf personality" so to say. In the 1960s the perspective was displaced beyond deafness in

itself, towards the socio-emotional embedding of deafness. Again, the Deaf-Deaf paradigm was instrumental in this context If it could be shown that Deaf children of Deaf parents functioned superior in psycho-emotional terms, the viability of the Sign language alternative was established, so it was assumed Most psycho-emotional studies performed since have operated "self-concept" or "self-esteem" as central parameters An additional prevailing research model was based on the psychodynamic theories by Bowlby and other leading developmental psychologists (Bowlby 1969, Broesterhuizen 1992). It should be mentioned however that neither of these theoretical frameworks is free of criticism (Hays 1998, Eyer 1996; Dawes 1994). The phenomenological basis for the self-esteem study design can be easily understood in the context of deafness. The oral method submerges a deaf child in a climate in which only one thing counts really speech Yet it is exactly (and only) this, which a deaf child cannot do or cannot do as well as hearing peers As a result such circumstances *must* lead to a negative self-image, it was felt intuitively. In theoretical terms self-image is perceived as the attitude one has toward the self, an attitude that is the product of self-evaluation (Gecas 1983) In terms of the Mental Incongruence Theory (MIT) one could argue that this evaluation involves an interaction between "cognitions" (experiences, observations, knowledge and appraises of reality) and "standards" (wishes, values, norms and ideal self-image). While several authors believe that self-image allows *some* incongruity with social reality, thus providing a "psychological buffer" so to say (Ziller 1969; Gecas 1985), it is also held that the social environment is a leading context· self-image *must* be congruent to some degree with real-life social opportunities and experiences (Rogers 1951, Mead 1934; Fitts 1964). As stated, the main premise of self-concept research in the context of deafness has been that a significant tension between cognition and standards may arise This premise was derived from the large body of research on the self-image of ethnic minorities, most importantly African-American youth, which lead to segregational educational strategies under the slogan "splendid isolation" (Dronkers 1997). A deaf child growing up in a family of hearing parents and attending an oral school for the deaf is likely to develop standards that are based strongly on oral achievement while his or her experience will learn that these standards are non-achievable, thus resulting in an "injured" sense of self The Deaf child of Deaf parents attending a signing school for the deaf on the other hand will internalize standards which do not include spoken language or any other form of deviance for that matter, thereby yielding a much more "positive" sense of self

Myklebust was one of the first to operate the concept of self-image in a deaf context (Myklebust 1960) As compared to non-deaf individuals he reports a less developed self-concept. Many other authors have since reproduced his findings (Blanton 1964; Craig 1965; Sussman 1973) Nonetheless Wright has reported contradictory evidence (Wright 1981) In either case, Myklebust's findings triggered follow-up studies operating the Deaf-Deaf paradigm. The studies by Stuckless (1966) and Vernon (1970) have been much cited in this context Both studies reported that Deaf children of Deaf parents did much better in terms of self-concept. In general the social environment of deaf children of hearing parents has been pointed out as the factor to blame (Schlesinger

1972, Loeb 1986, Altshuler 1974) Schlesinger focussed on the inadequate communicative skills of hearing parents, Loeb pointed at the sub-optimal child-parent bonding while Althuler believed that parental denial and depression were the main contributors

As one could expect, the above-mentioned studies ignited the educational debate If indeed Deaf children of Deaf parents were better adjusted psycho-emotionally and if they outperformed deaf children of hearing parents in cognitive terms, what were to be the consequences for the education of deaf children? Manual language advocates felt that the findings urged the introduction of manual language to *all* deaf children In addition it was felt that the findings argued against the trend of mainstreaming Farrugia supported this latter conviction with the empirical finding that deaf children mainstreamed in hearing schools had lower self-esteem compared to those attending a residential school for the deaf (Farrugia 1980) All in all these research findings led to the conviction that the solution to the "deaf problem" was to be sought in providing Sign language early on Deaf role models, residential schools for the deaf, Deaf empowerment, and the cultivation of the concept of Deaf culture are all derivatives from this idea (Luckner 1987)

Indeed, the early 1970s marked a clear chance of path for many deaf schools as many incorporated manual language into their program (Geers 1984, Tellings 1995) Initially most programs optioned for a manually coded form of the dominant spoken language, a method commonly referred to as Total Communication (TC) or manually coded language (for example NmG, Nederlands met Gebaren) In some respects TC appears to have been a compromise between oralism and manualism What many oral advocates feared was that exclusive Sign language instruction would result in a complete failure of spoken language development These fears were not only socio-linguistic in nature (low threshold of Sign will draw children away from spoken language) but also based on the lack of compatibility between true Sign and spoken language Since for most the outlook of spoken language and the opportunity of integration was valued indeed (Tellings speaks of "free-choice manualism" in this context), TC was perceived as the best way to safeguard this goal while also catering to the above mentioned empirical findings in favor of manual language (Tervoort & Van der Lem 1981, Broesterhuizen 1992) Contrary to true Sign language, Total Communication followed the grammatical structure of spoken language and incorporated mouth gestures in its form It was therefore perceived as an instructional method, which added to both the manual and oral proficiency more or less simultaneously

Soon after the implementation of Total Communication however, studies appeared that indicated that the TC method failed to realize its promises (Allen 1986 Tellings 1995, Broesterhuizen 1992) A landmark publication in this respect was the study by Allen, who compared the reading abilities of exclusively orally schooled with TC educated deaf children and found only small differences between the two groups (Allen

1986) Though many of these studies were small and sensitive to selection and method bias (not all TC programs used spoken language in similar intensity), it seemed that children in a TC setting achieved even lower levels of usable spoken language skills as compared to those enrolled in a classic oral program (Geers 1984, Jensema 1978, Musselman 1988) As we mentioned in the introduction of this section, many advocates of manual instruction have argued that oral skills *will* develop after proficiency in manual language is established To test this hypothesis the US National Institutes of Health sponsored a study involving 227 16-17 year old deaf students that differed in educational background (Geers 1989, Geers 1992) The study was performed in a joint effort between the Central Institute for the Deaf, who provided the oral students, and Gallaudet University who provided the TC students Geers reports that students who attended an oral program outperformed those in a TC program on such items as word recognition, lip-reading, speech intelligibility and oral language proficiency Interestingly, this superiority was maintained when compared to Deaf children of Deaf parents attending a TC program In terms of speech intelligibility Geers found that TC children with pure-tone thresholds in the 80-90 dB range did not even equal orally educated children with profound losses (> 110 dB) Advocates of the manual method however maintained that TC would not injure the ability of deaf children to master oral language skills (Caccamise 1978, Wilburn 1979, Schlesinger 1972, Vernon 1970) The empirical findings that were to support this conviction have been criticized to exclude speech intelligibility (Geers 1992)

The interpretation of the above-mentioned empirical findings appears to have been twofold On the one hand it functioned as a reassurance to oral programs Since TC failed to establish itself as an equal of an exclusively oral education, the legitimacy of the oral method was upheld, some believed On the other hand, those in favor of manually based instruction blamed the results on the TC-theorem itself, which was considered a hybrid or "pidgin" theorem in linguistic terms As such the results paved the road for *true* Sign language instruction and bilingualism (Knoors 1989, Broesterhuizen 1992) The latter is a method in which true Sign language was to be combined with oral language, in spoken or written form Another point of reference that played a significant role in the debate was bilingual-linguistics, which claimed that the best perspective of "additive bilingualism" (in hearing populations) would be attained in sequential rather than simultaneous exposition to language-1 and language-2 The exact implications of Bilingualism-Biculturalism (BiBi) however, often remain unclear Indeed as Tellings notices, some advocates of the BiBi theorem appear to promote a unilingual method really, with only little attention to the written form of the spoken language, a position she identifies as "strict manualism" (Tellings 1995) While the promotion of the concept of BiBi is becoming widespread, there is a lack of explicit methodology

In either case, the net effect of the disappointing results of TC has been that many schools for the deaf prepared the introduction of true Sign language in their educational system Only 20 years after its introduction, TC was abandoned and slowly replaced by

Sign language instruction in 4 out of five schools for the deaf in The Netherlands in the 1990s In the wake of these developments, academic efforts to educate or re-educate personnel prospered In 1999 the Dutch Sign language Institute was founded, an institute which was to coordinate Sign language education at an academic level as well as promote research Also, the need for one form of Sign language arose as well as the demand for formal recognition of Sign languages Though small the country may be, uniformity in Sign languages was lacking in The Netherlands The Sign languages spoken by Deaf communities surrounding the various deaf institutes all appeared to have their idiosyncrasies, hence triggering standardisation efforts In 1997 the Commission on Dutch Sign Language published its report "More than a sign", which was to become the "political manifesto" to attain minority language recognition of Sign language in The Netherlands (Rapport van de Commissie Nederlandse Gebarentaal 1997) In the wake of this report, all deaf schools in the Netherlands signed a covenant supporting bilingualism in 1998 This covenant implies that bilingualism has become the official philosophy of deaf education in the Netherlands

The Disability Rights Period

The closer history documentation approaches the current time frame, the more difficult it becomes to provide an accurate view on events Thus, to classify our modern time as one in which "disability rights" lead the way, is by definition a tentative initiative Where deaf education is heading and how current events and debates relate to this direction is simply not entirely clear Nonetheless there are some clues that may be of value in this context

We have classified our modern days as a period in which disability rights have taken a leading role in the debate on deaf education The disability rights view is a direct derivative of the civil rights movement that gained momentum in the 1960s and 1970s There are some concrete indications that at least the political representation of people with disabilities is currently strongly influenced by the civil rights movement The disability rights movement strongly relies on political as well as juridical premisses Indeed in the present-day situation in The Netherlands these premisses are increasingly becoming the dominant arenas in which the interests of people with a disability are defended Politically enforced positive discrimination and affirmative action acts and legal procedures against those deemed damaging to the social image of people with a disability appear to be on a rise When the Dutch Society for Ideal Advertising (SIRE) aired their yearly television campaign regarding the potential disabling effects of fireworks in December 1999, they encountered fierce critique from the disability movement The campaign featured adolescents with clear stigmata of fireworks accidents, such as missing fingers or hands It also showed how their peer group socially isolated these victims The Dutch Disability Council publicly renounced this "pitiable image" of people with a disability One of the best-known events that illustrate the new

path deaf advocacy has taken is perhaps the 1988 students uproar at Gallaudet University Some perceive of this event as a major turning point, a turning point towards a disability rights discourse in our view The uproar was instigated by the appointment of Elisabeth Zinser as the college's new president Zinser, a non-deaf administrator at The University of North Carolina, was chosen over two deaf candidates and staff members at Gallaudet, I King Jordan and Harvey Corson Students at Gallaudet rallied against this decision, pleading for the appointment of a deaf president as well as a 51% deaf representation in the college's board Through demonstration and political lobbying, the board of the college eventually withdrew its decision and appointed I King Jordan as president of the college

The deaf differ from most other people with a disability in the sense that they commonly form a cohesive social group and communicate in a distinctive language It appears that because of this the case of the deaf is to some extent exemplary for the disability rights movement Today, advocacy of Sign language is very much similar in discursive structure to advocacy of other minority languages, an issue on which we will elaborate in chapter seven While advocacy of Sign language previously upheld the notion that acquisition of spoken language skills and social participation are paramount values if reasonably attainable, the disability rights movement debate renders such a conviction more or less obsolete what is at stake is the right of *unrestrained maintenance* of a cultural and linguistic minority While the disability rights discourse is encountered widely in the deaf education debate, Lane has become its leading, most thorough and most eloquent spokesperson In The Mask of Benevolence, Lane draws frequent parallels between the Deaf and other (ethnic) minorities (Lane 1992) Clearly, Lane embraces the theoretical underpinning of the civil rights movement He prefaces his work with an excerpt by French Constructivist Foucault, from whom he also derives the title of his book

> The real political task is to criticize the working of institutions that appear to be both neutral and independent, to criticize them in such a manner that the political violence which has always exercized itself obscurely through them will be unmasked so that one can fight them (Michel Foucault, 1974)

Another important development took place at about the same time as the disability rights movement gained momentum and Sign based instruction found its way to deaf schools the introduction of cochlear implantation By the end of the 1980s implant teams around the world started to include prelingually deaf children into their programs In 1995 the National Institutes of Health issued a consensus statement in which prelingually deaf children were considered suitable candidates for cochlear implantation By the early 1990s reports on the first large cohorts from Iowa, Nottingham and Hannover were published In the Netherlands, the Nijmegen University Hospital (AZN)-Sint Michielsgestel Institute for the Deaf (IvD) implant team pioneered pediatric cochlear implantation From these studies it appeared that cochlear implantation in pre-lingually

deaf children was neither experimental nor unsuccessful The increasing number of implant receivers indicated that the procedure was consolidating, thereby drawing more and more attention to the issue by those in favor of Deaf culturalism, the specific variant of the disability rights discourse Since cochlear implantation is aimed to allow profoundly deaf children access to spoken language and as such requires explicit training of oral language skills (Wever 1998), many considered it at odds with the civil rights discourse described above Perhaps the most distinct manifestation of Lane's civil rights foundation can be found in his 1997 publication in the Kennedy Institute of Ethics Journal (Lane 1997) In this paper Lane discusses the hypothetical case of the "perfect cochlear implant", an implant that would truly allow spoken language development on par with hearing children Lane persists that cochlear implantation would remain morally reprehensible, even under such "ideal" circumstances

Framing history

In general the position of deaf people prior to 16th century is not well known Nonetheless it appears to be commonly assumed that the pre-modern period represents the "Dark-Ages" for people suffering from hearing loss, at least it appears that this dystopia-image is its metaphoric function in debates on deafness (Bell 1998) The Dark Ages metaphorically represent a state of myth, religion, social injustice and a general lack of rational understanding as opposed to the liberated scientific views and humanist social-political attitudes of the Enlightenment Likewise, deafness in the pre-modern era is portrayed as surrounded by myth and guilt, a lack of understanding and cruel social segregation For authors who support Sign language, this depiction of the pre-modern period fits well into the general theme of struggle and advancement and functions as a symbol of danger, of where we will end up if the focus on empowerment is abandoned (Moores 1998)

Sicard directed the deaf school founded by l'Epee in Paris after the latter passed away and several other schools were founded in this tradition Lane states that around all of these schools a Deaf community thrived in the 19th century

> Each new school for the deaf was like a planet that revolved around the sun - Saint-Jacques - yet had its own satellites, for each attracted not only deaf pupils, faculty, and staff, but also deaf adults in the community In the nurturing atmosphere of each of these planets there evolved in time a fully developed deaf community, lettered and cultivated through the medium of manual language [ ] It was Berthier [deaf teacher in Paris - ccw] who built a bridge from the citadel of sign on the rue Saint-Jacques to the larger and more diffuse signing society in Paris, one that counts, among its more successful members, writers, publishers, painters - some with work on display at the Louvre - artisans, and businessmen To enhance the lives of these adult deaf people through legal reform, education, and fund-raising, Berthier created the first known social organisation of the deaf He was also vice-president of our first welfare organisation and he is a member of literary and historical

> societies. For several decades he has addressed a stream of letters to the legislature protesting laws unfair to the deaf (Lane 1984, 112-113)

Hence, it is assumed that the 18th and 19th century represent the "Golden Age" for deaf people, yet this belief is not entirely factual, perhaps even functions as a rhetorical utopia to some extent. First of all, though Lane and others have familiarized us with some 18th and 19th century deaf scholars, little is known about the *typical* state of deaf people let alone how this compares with the typical state of deaf people today. Lane does not provide numbers and it is questionable if one can indeed. Winzer also states that "little is known about the experiences of disabled adults in the nineteenth century" (Winzer 1993). Besides the fact that accurate records are not available (not even today) to make such a comparison, one would have to discount for likely changed definitions of deafness as well as changes in etiology of deafness. It may well be, for example, that 19th century deaf schools harbored what we would today call the hard-of-hearing in addition to profoundly deaf. Based on Winzer, it appears that the state of the deaf was not as supreme as Lane suggests. Provisional compounded data (n = 1059) from five schools for the deaf (American Asylum, Clark Institute, Kansas-, New York- and Ontario schools for the deaf) reveal that only 4.2% of deaf graduates held professional positions and 3.8% white collar jobs. The large majority was involved in semi-skilled (34.7%), unskilled (12.9%) or agricultural professions (9% skilled, 21.8% unknown). Moores claims that "fewer than half" of all deaf children "ever set foot in a school for the deaf", that most deaf children did not start their educational career up to the age of ten and that the average school enrollment was often limited to about five years (Moores 1998).

Still Lane's discourse is highly effective from a reader point of view. Lane succeeds brilliantly in creating a colorful atmosphere and moulding the complex issue into universally appealing themes such as good versus evil, philanthropy versus egocentrism, emancipation versus oppression while alluding to emotion of righteousness, pity, guilt and penance (Moores 1998). By doing so he channels the debate in a moral absolutism in which only two options are available: the right choice and the wrong one – as we will show in this thesis, this is a central issue that continues to influence the deaf educational debate. No space is left for greys or nuance: the issue is one of admitting color really. By narrating extensively on the downfall of the manual Golden Age in the nineteenth century, Lane creates a mirror without explicitly saying so. This is not only a historical text, but also the story of our modern day Lane appears to convey (Moores 1998). Writing his text at the dawn of a new era of Sign language dominance, Lane utilizes his text to fuel this still vulnerable movement by drawing the phantom of the Milan conference. His follow-up publication The Mask of Benevolence and his subsequent attack on cochlear implants work so well because of the ground work of When the Mind Hears (Lane 1992; Lane 1984).

Conclusions

This summary of the history of deaf education provides several insights that are of importance to retain throughout this thesis since the contemporary debate surrounding pediatric cochlear implantation makes frequent reference to this eventful history. We would like to highlight some aspects of interest.

The history of deaf education reveals an ongoing struggle in methodology, between "manualists" and "oralists". Throughout history there have been advocates of both positions and not rarely did these advocates engage in passionate debates. Furthermore it appears that these debates were often characterized by a strong personal tinge, as they were pursued by historically almost iconoclastic individuals. De L'Epee and Pereire were such a remarkable couple in 18th century France. Bell and Gallaudet have shaped the debate in 19th century America. Tervoort and Van Uden embody the 20th century debate in The Netherlands. These individuals commonly were professionally active in the field of deaf education. The advocacy of a particular method thus often coincided with the method practiced in professional life. Lane is an exception to this rule as he was an accomplished psycholinguist well before publishing "When the mind hears", only dealing with the issue of deafness as an *extracurricular activity* so to say. Even though Bell's interest in the issue did have a solid personal background, he too was not professionally involved with the education of deaf children. It can be assumed that advocacy of a specific method cannot be perceived independently of the personal situation. While we would not want to question the authenticity of any spokesperson's crusade, there is a definite personal component involved that may at least explain the ferocity and rhetorical nature of the argumentation. If, for example, De L'Epee did not outline his position as strongly as he did, he may have lost state sponsorship of the school he headed. In the Netherlands, many pupils of Tervoort now hold leading positions in the field of deafness. It may be questioned if they would have attained these positions if they had not drawn the debate into a rhetorical arena. It appears that this situation aggravated the dug-in positions and trench warfare, which are frequently encountered in the deaf educational debate.

The fact that so many spokespersons make a living on educating deaf children may also be of significance from another perspective. It has been observed that teachers of disabled children practice their work with great devotion. This is a wonderful thing in itself but may become an issue of concern if it is combined with public advocacy. Deaf education is a relatively secluded practice. The physical isolation of the institute does not only affect the pupils but professionals as well. The rhetorical framing of the educational debate is also encountered in the methodology of deaf schools. Schools often champion themselves as being "oral" or "manual", at least they used to up to very recently. Given the devotion of deaf teachers, the relative isolation of deaf schools and the fact that many deaf schools incorporate a *specific* methodology, it appears conceivable that group-dynamics will strengthen rather than nuance the rhetorical nature of the debate. This may

lead advocacy into the realm of faith. While conventional pedagogical strategies have at best only partial effect on the well-being of a child, this is not the case for deaf education. The choice for manualism or oralism inevitably has a strong influence on a deaf child's future. It is not hard to imagine how this may place a considerable burden on the shoulders of those responsible. Yet the true issue at hand, the well-being of deaf children, is a complex one, one that is fickle compared to the simplistic outline of the rhetorical debate. Moreover, the results of any given method do not manifest themselves directly but are rather postponed in time. To believe wholeheartedly in the method one practices may thus also be intensified by the vast stakes of the game, the well-being of deaf-children, as well as the uncertainty surrounding it.

Deaf education eloquently reveals the significance of Kuhn's view on science and social progress. The turn towards Sign language in 18th and 19th century France appears to be at least in part the result of the cultural climate of the time as well as the more or less contingent interest of an individual in the language of the Deaf rather than breakthroughs in science. The events surrounding the previously mentioned Milan Conference delineate particularly convincingly how significant social change cannot be explained based on scientific truth exclusively and vice versa. As Lane outlines indisputably, the result of this conference was influenced strongly by the composition of the attendants of the conference, yet it was to influence the social reality of deaf education as well as the direction of scientific inquiry for decades. Kuhn's view continues to clarify the course of deaf educational history in the twentieth century. While Stokoe as well as others provided landmark knowledge about the language of the deaf, the wake of events which took place after Stokoe cannot be understood based on these facts alone.

BEING DEAF IN THE 20TH AND 21ST CENTURY

Introduction

What does it mean to be deaf in the 20th and 21st century? What language do deaf people speak predominantly, where do they socialize, what educational status do they attain, what job perspectives do they realize and what can be said about their quality of life? All of these questions are relevant as they provide the backcloth of the debate on deafness today Yet for many reasons it is not a simple task to describe the deaf population in our modern times One of the reasons for this is that few cross-sectional studies have been performed and even less longitudinal follow-up studies Another complicating factor is that definitions of "deafness" tend to vary somewhat thereby clouding our understanding of the issue Furthermore the adult deaf population is not uniform in some determining characteristics, as Braden has shown (Braden 1994) To name a few factors a relatively high proportion of the deaf population has additional handicaps, IQ and SES are variable, the mode and quality of education varies and internationally different educational and legal resources are available to deaf people Cates and Braden feel that these factors should be accounted for, yet cross-sectional studies often do not provide the power and sensitivity to do so (Cates 1991b, Braden 1990) Moreover such studies are sensitive to selection-bias Recruitment of respondents through deaf school alumni archives is likely to exclude those who were mainstreamed Peer recruitment risks selecting a relatively emancipated population Nonetheless quite a few general facts can be derived from the literature For further in-depth reading we refer to Paul & Jackson (1993) and Broesterhuizen (1992) In spite of these complications, we will draw a global image of deafness in this section

Deaf culture & Sign language

One popular assumption is that adult deaf individuals rely strongly on deaf peers in socio-cultural terms Leisure time is spend mostly within this environment, and it is also stipulated to be deaf peoples' main resource for friendships and relationships This socio-cultural unity is commonly referred to as Deaf culture, a minority culture with its own unique language, Sign language

In the Netherlands 58,5% of deaf and hard-of-hearing adults report that more than half of their friends are also hearing impaired and 75,7% is a member of a deaf or hard of hearing organisation (de Graaf & Bijl 1998) Schein and Delk found that 89% of pre-lingually deaf American men and 93% of deaf women are married to a deaf or hard of hearing spouse (Schein & Delk, 1974) From this latter study it appears that the age of onset of deafness confounds the likeliness to marry a deaf person post-lingually deaf

individuals were less likely to be married with a deaf or hard of hearing spouse. In de Graaf's study (n = 523) 31% reports a partner with a hearing disability, though it should be mentioned that 32,7% of the sample had hearing loss ≤ 90 dBHL and 40% acquired deafness post-lingually (de Graaf & Bijl 1998). An IvD alumni survey showed that 50% is married to a deaf spouse (Diemer 1992).

Regarding the role of Deaf culture, Bat-Chava argues that 3 groups of "deaf people" can be identified within the American population (Bat-Chava 1992): Culturally Deaf (33%), biculturally deaf (34%) and deaf people with a hearing identity (24%). An IvD survey showed that many deaf alumni socialize with both deaf as well as hearing friends (Diemer 1992). 76% of respondents attested to have deaf friends while 75% had hearing friends, 44% said that their best friend was a deaf person while 40% said it was a hearing individual. It therefore appears that Deaf culture is not the *only* social reality available to deaf people. Some of the most common explanations for the fact that many deaf individuals restrict their social circle to deaf peers have been: 1) communication breakdown and 2) exclusion by prejudice or unfamiliarity. The first issue can be found in the narratives of deaf adults (van Noort 1999; Higgins 1987; Hindley 1993). The second has been explained as self-segregation as well as active exclusion by the hearing (Levy-Schiff 1985; Hindley 1993). A third, less heard of, option is the early and enduring exclusive socialisation in the deaf peer group, which occurs in the residential school setting. Indeed attending residential school is a main prerequisite of Deaf culture (Higgins 1987; Hindley 1993). The fact that many of the most thriving Deaf communities are within close range of a residential school for the deaf and the fact that these communities may even exhibit unique Sign language dialects also support this thesis.

Regarding the use of Sign language few large studies have been conducted and the numbers available are generally less convincing than the Deaf culture argument discussed above. Making a fair estimate is complicated by the question what comprises Sign language: is for example TC also to be considered "Sign language" or are we to operate the linguistic definition more strictly? Furthermore it may be that some deaf people use Sign language as well as spoken language, depending on the situation: are we to categorize such people as "Sign language individuals" or not? Finally the numbers found will likely depend on the age at which deafness was acquired as well as the severity of hearing loss. Many studies mix profound deafness with less severe forms of hearing loss and often no disciplined distinction is drawn between prelingual and postlingual deafness. In The Netherlands 34.2% of deaf and hard of hearing adults claim proficiency in Sign language while 60,4% claims at least a good command of oral-aural skills (de Graaf & Bijl 1998). However, since post-lingual deafness was not excluded in this study and the likelihood of Sign language use is smaller in the latter group, these numbers are likely to pivot towards Sign language if post-lingual deafness is excluded. Seemingly many but not all deaf individuals associate themselves with Deaf culture and only a minority relies on Sign language exclusively. Indeed Kyle and Allsop found that while almost all deaf adults feel that Sign language instruction is crucial in deaf

education, many respondents also valued spoken language skills (Kyle & Allsop 1982) While causing surprise to some authors who apparently believe that culturally Deaf individuals do not value spoken language skills, almost 4 out of 10 respondents felt that parents should exclusively use spoken language with their child to promote lip reading skills (Hollman-Borsje 1990) Indeed in-depth interviews with five prominent Dutch deaf respondents revealed that spoken language is valued (van Noort 1999)

The assumed dominance of Sign language has been argued through several channels, which may be grouped under the umbrella of the "natural language" concept Tellings has shown that a wide variety of meanings are attributed to this concept (Tellings 1995) It appears that this concept sprouted from general linguistics (de Houwer 1995) It is postulated that deaf children must be offered language access in a "natural environment", rather than a formal-pedagogical environment Most assume that the only first language that qualifies is Sign language (Bornstein 1973, Vernon 1970) Yet others have postulated that it can be spoken language as well (Geers 1988) Some feel pragmatically that most deaf children simply cannot realistically be expected to master spoken language as the direct result of their handicap (Loncke 1985) It has been claimed that, depending on the severity of hearing loss, only about 15-30% of all deaf children will succeed in oral language (Braden 1994, Conrad 1979, Dowell 1995) The relation between degree of hearing loss and the chance of developing spoken language has been shown repeatedly Studies reveal a rather steep decrease in spoken language opportunities beyond 90 dB loss Olsholt and Falkenberg report for example that 40% of their respondents with more that 90 dB hearing loss scored none of the 25 items based on oral-aural information alone, while almost half of respondents with thresholds below 90 dB scored more than 20 items correctly (Olsholt 1988) Others have argued that deaf children have a natural talent or preference for Sign language, a talent that materializes even in the absence of a signing environment While all small infants use some form of gestures, deaf infants are believed to do so more prominently Nonetheless Spencer failed to confirm such a preference in the pre-lingual phase (Spencer 1993) Furthermore, an early preference for signs does not *equal* Sign language Perhaps the lack of support for a natural preference for Sign language can be explained by the lack of exposure to this language in most deaf children, since about 85% of pre-lingually deaf infants have two hearing parents (Gallaudet survey 1999-2000) Indeed it has been abundantly shown that Deaf children of Deaf parents make far greater headway in Sign language as compared to children born to hearing parents It appears that early and intensive exposure to Sign language explains this finding In particular informal non-pedagogical communication has been found to lag behind in children of hearing parents (Bodner-Johnson 1991, Moseley 1990)

In sum, the socio-cultural reality of the adult deaf is rather diverse though pitched towards the socio-linguistic group defined by Deaf culture A majority of pre-lingually deaf adults socializes with other deaf people primarily and about 9 out of 10 have a deaf spouse Severity of deafness and early Deaf culture exposure are likely positively related

to this phenomenon. While a large portion of deaf adults socializes with deaf peers primarily, a substantial number also engage in hearing society. It hence seems that the socio-cultural space of a substantial number of deaf adults is considerably wider than is often assumed. The role of Sign language is difficult to describe because of conceptual confusion. From the material available it seems that only few deaf adults rely on Sign language *exclusively* even though sign-based communication is listed as primary language by a majority of deaf people. Hence, manual communication is important for deaf adults, yet this does not exclude oral-aural communication by definition. The most profoundly deaf are more likely to communicate through manual channels exclusively.

Mental health

It is assumed that many or even most deaf individuals cannot master spoken language even under the most ideal circumstances. Indeed deaf educators seem to agree that for the most severely deafened individuals the yield of an oral education is often rather marginal. In addition it is felt that rigorous oral training has distinct liabilities, most of which are defined in psycho-emotional terms. Several cross-sectional studies have shown that the incidence of psychopathology is relatively large in adult deaf populations (Hindley 1993; Eldik 1998). Freeman and colleagues found that the incidence of psychiatric disturbances was three times higher in deaf children as compared to hearing peers (Freeman 1975; Broesterhuizen 1992). Based on teacher evaluations the authors found that 11.6% of deaf subjects (n = 516, 4-20 years of age) were categorizable as "seriously disturbed" compared to only 2.6% of hearing subjects. A recent Dutch study revealed that 27,3% of deaf men and 36,8% of deaf women reported psychological problems (de Graaf 1998), which compares unfavorably to the hearing population (22% and 26,6% respectively). Severity of hearing loss did not modulate this finding. Vostanis estimates the prevalence of psychopathology to be as high as 40% (Vostanis 1997). Interestingly Vostanis also found that if the deaf individual mastered some spoken language skills, the risk for psychopathology decreased. De Graaf et al. did not find such a protective effect of spoken language proficiency nor did they find a beneficial effect of Sign language in adults with severe hearing loss. De Graaf did find that post-lingual deafness is a higher risk for psychological problems.

The high incidence of psychopathology has been explained in terms of a language-deprived childhood mostly. Since most studies have neglected possible confounders and have been cross-sectional in set-up it cannot be excluded however that the source of emotional strain is explained by the institutionalisation experience or the adult experience of isolation and marginalisation. Higher incidence of communication problems is a risk factor for psycho-emotional suffering as is a low level of educational achievement and a high level of social orientation on the deaf or hard of hearing peer group (de Graaf 1998). Additionally, the high incidence of compounding handicaps, about 30-40% of deaf children have additional handicaps (Hindley 1993; Pollack 1997;

Gallaudet survey 1999-2000), may in part explain the results (Meadow 1980, Hindley 1993) Regarding this latter issue we refer to the study by Vernon who screened 1468 deaf children enrolled at the California School for the Deaf in the 1950s and 1960s (Vernon 1969, Broesterhuizen 1992) The incidence of retardation was 7 times that of the normal population (17 9% versus 2 5%), cerebral palsy occurred 33 times more often (6 7% versus 0 2%) and an additional visual handicap was even 170 times more likely to occur (17 1% versus 0 1%) Vernon attributes the high incidence of additional handicaps on rubella, prematurity, meningitis and rhesus-antagonism, all of which constitute non-genetic deafness, which seems to suggest a lower incidence of additional disabilities in Deaf-Deaf children (Hindley 1993) Craig reports 9% learning disabilities, 8% intellectual disabilities and 4% behavioral disabilities (Craig 1993) Additional handicaps are a risk factor for cognitive under-development as well as emotional dysfunctioning (Jensema 1975, Goulder 1977, Broesterhuizen 1992, Hindley 1993) Zwirecki and colleagues submitted 88 selected deaf children (based on behavioral problems, learning disabilities and other factors) to neurological tests and found that 40% exhibited clear neurological symptoms while 84% manifested abnormalities on EEG (Zwirecki 1976, Broesterhuizen 1992) Hindley concludes that the best estimate of brain damage in deaf children is about 10% (Hindley 1993) This had led authors such as Klinghammer to conclude that not only cognitive deficits but also psycho-emotional disturbances in deaf populations are likely neuro-psychological in origin rather than psycho-developmental (Klinghammer 1978, Broesterhuizen 1992) Others feel that both aspects are of importance, which seems a reasonable conclusion (Hindley 1993)

In sum, deaf people are more at risk of psychiatric and psychological morbidity than hearing peers It remains rather unclear which factors are responsible for this finding Some have argued that spoken language proficiency protects against emotional problems Others feel that early language deprivation is to blame Since most studies have been cross-sectional and aimed at adult deaf subjects, the negative influence of factors that are not intrinsic to deafness, such as social marginalization, institutionalisation and additional disabilities, cannot be excluded As such it appears premature to attribute psychiatric morbidity of deaf adults to their oral-aural mode of communication during childhood exclusively

Self-concept

Related to the prevalence of psychopathology is the issue of self-concept and self-esteem, which has come to the forefront over the past 40 years or so Myklebust was one of the first to study self-concept, using the Minnesota Multiphasic Personality Index or MMPI (Myklebust 1960) His study reported that deaf people have a less developed self-concept, an "injured-self", as compared to hearing individuals Blanton (1964), Craig (1965), Schlesinger (1972), Sussman (1973), Altshuler (1974) and Loeb (1986) reproduced these findings Garrison and colleagues disagree with the dominant views on

the relative weak self-concept of deaf-hearing children their belief is that this finding is likely the result of the language backlog of deaf-hearing children since instruments such as the Tennessee Self-Concept Scale are not adjusted for Sign language (Garrison 1978) De Graaf found that the self-reported low self-esteem by deaf adults is a risk factor for psychological problems (De Graaf 1998)

The relatively weak self-concept has been attributed to the social and language environment in which deaf children, those born to hearing parents in particular, are raised It has been argued to be in part the consequence of an over-exposure to the dominant disability image of deafness held by hearing society casu quo an under-exposure to the more positive self-concept attributed to Deaf culture This perspective has been expressed by Baker (Baker 1997)

> ASL is the language of Deaf people throughout the United States Proficiency in ASL automatically allows membership in the Deaf Community and in cultural events that occur in communities where Deaf people live This membership is vital to Deaf children because it promotes a healthy view of who they are as human beings and increases self-esteem and confidence in their abilities to interact in a wide array of situations (Baker 1997)

Indeed Meadow and others have reported a more positive self-concept in Deaf-Deaf populations as compared to deaf-hearing individuals (Meadow 1967) Regarding the micro-environment, hearing parents have been much under scrutiny as the development of a healthy self-concept is believed to be a parental task and children of Deaf parents appear to be doing better in these terms (McElroy 1978, Stuckless 1966, Vernon 1970) even though some have contested this (Kelliher 1976) In terms of educational placement, conforming to the debate surrounding ethnic minorities (Herrstein 1994, Dronkers 1997), mainstreaming is perceived by some as a source of a weak or negative self-concept (Hindley 1993) Farrugia provided empirical evidence for this thesis, yet others have failed to reproduce it (Farrugia 1980, Ndurumo 1980, Carey 1986, Beaudoin 1984) Ndurumo as well as Carey - the latter using the Meadow-Kendall scale adapted for deaf respondents - even found a favorable self-concept in mainstreamed deaf students (Ndurumo 1980, Carey 1986) Cole found a somewhat favorable impact of a "bicultural identity" (Cole 1991, Broesterhuizen 1992)

Nonetheless, these findings have led some authors to argue in favor of empowerment, educational attention to Deaf culture and early exposure to Deaf role models (Luckner 1986) The resultant relative isolation is believed to be of benefit ("splendid isolation") more than it is a liability, something which Sansone appears to reject as he feels that the isolation of group-orientated strategies will result in a "therapeutic environment" (Dawes 1994) or "glittering in the shadow" (Sansone 1992) Indeed some Deaf spokespersons have attested just this Dutch spokeswoman van den Garde for example claims that an important motive to choose for Deaf culture submersion is to arm the deaf against the inevitable disappointment when meeting the hearing world (van Langen 1996) Beaudoin however found a relatively low self-esteem

in 6 exclusively signing Deaf adults, which he attributes to the fact that these individuals were sent off to a boarding school for the deaf early on (Beaudoin 1984). Indeed, in other settings, institutionalisation has abundantly been shown to be a source of psycho-emotional liabilities. De Graaf found that a minority of deaf adults (36.4-39.2%) graded their deaf boarding school experience as pleasant (De Graaf 1998).

We conclude with the observation that self-concept and self-esteem are concepts that provoke controversy in the scientific community (Dawes 1994). While few are likely to argue that the concept should be discarded altogether, many have questioned the way in which it is applied as well as the conclusions drawn from it in an empirical setting. Psychometric concepts such as self-esteem and loneliness are of interest, as they are believed to be related to mental health through their respective theoretical frameworks. Many scientists around the world have spent, and are still spending, entire careers in both designing valid instruments for the concept as well as reasoning about its significance or lack thereof (Gecas 1983: Gecas 1985; van der Zouwen 1987). Simply applying these concepts to a very practical research question and even extrapolating far reaching interventions from its results does not acknowledge the work performed by theoretical social-psychologists nor does it account for the status of the concepts. Especially in a study population with a strong emancipation discourse the risk of measuring *social discourse* seems real (Gecas 1983). The fact that the questions on self-concept instruments are typically rather straightforward and that many deaf people are well acquainted with the thesis of low self-esteem as well as the potential of enhanced self-esteem through Sign language, makes interpretation difficult (van der Zouwen 1987). Nonetheless the public appeal of results of self-esteem studies appears to be instant, evident through the general lack of a critical attitude towards applied self-esteem research, which suggests that self-esteem has become an integral part of our socio-cultural discourse on how to live well: a positive self-image is a sought after commodity in our postmaterial quest for *the good life*, thereby making it a moral rather than an empirical concept (Bell 1998).

In sum, many authors have reported a less developed self-concept amongst deaf adults. It has become popular to explain this finding in terms of a lack of positive reinforcement: deaf people suffer from the negative stereotype of disability dominant in hearing society. As such it has been the cradle of the advocacy of early Deaf culture submersion, which provides a positive environment for identification. Yet the data supporting an uncomplicated and causal correlation between early Deaf culture submersion and a positive sense of self is incomplete. Some authors for example, have reported a positive impact of bicultural orientation and educational mainstreaming. Moreover, the segregation that Deaf culture submersion requires may be criticized on moral grounds as well. It seems that in the context of deaf studies, self-concept has often been used too thoughtlessly to produce support for the case of early Deaf culture submersion.

Attachment

A third issue that has drawn attention is the quality of parent-child interaction in a deaf setting Numerous studies have compared parent-child interaction in a deaf-hearing setting to those in a hearing-hearing or Deaf-Deaf setting, many through observational studies Bowlby's *Attachment theory* in particular but also Bruner's *Shared-gaze theory* and Bates' *Symbolic play theory* have moulded most of these studies (Bowlby 1969; Brunner 1983; Bates 1979). The assumption of these studies can be well understood. since hearing parents lack proficiency in Sign language, the early communication with their deaf infant will necessarily be rather elementary and hence more "controlling" rather than effective and reciprocal, particularly if they communicate through oral-aural channels primarily (Brinich 1980, Broesterhuizen 1992, Beck 1996) Additionally the emotional response of caregivers in light of their child's handicap is postulated to predispose to a negative nurturing environment, which is believed to be of influence on the parent-child relationship Both situations, which are likely most outspoken in the sensitive earliest years (Bowlby's "attachment" takes place between 2 and 24 months), are assumed to have a negative impact on cognitive and socio-emotional development (self-esteem, social competence) of a deaf child as well as parent-child attachment (Paul 1993) A typical design has been to observe children's response to separation from and reunion ("strange situation") with their caregiver. Another common strategy has been to observe and register turn-taking behavior and negotiation in parent-child interaction and play situations. Greenberg found that oral deaf-hearing children were somewhat less securely attached compared to deaf-hearing children with whom some form of manual communication was used (Greenberg 1979). Galenson however *also* reports severe anxiety on separation in Deaf-Deaf children (Galenson 1979). Meadow on the other hand found that Deaf-Deaf children performed similar to hearing children in terms of attachment (Meadow 1981; Paul & Jackson 1993). Hindley explains these contradicting results on grounds of possible selection bias. Meadow's group was likely more "culturally Deaf" as compared to the group studied by Galenson (Hindley 1993). Another landmark study concludes that hearing mothers of deaf children tend to be "less flexible, less permissive, less approving, more didactic, more controlling, and more intrusive" than mothers of hearing children (Schlesinger 1972, Paul & Jackson 1993) Again Meadow and colleagues found no such differences in Deaf-Deaf dyads as compared to hearing-hearing dyads (Meadow 1981). On the other hand Lederberg recently found few differences between deaf-hearing and hearing-hearing dyads in terms of topic control and turn-taking control (Lederberg 2000) Finally we note that some have criticized the Attachment theory altogether (Eyer 1994) Though such an encompassing critique would seem unfair to the respected work of Bowlby and others, the utilisation of the concept may indeed be questioned Cross-cultural studies have for example revealed differences in mother-child interaction from an attachment point of view, thus arguing against a one-dimensional conceptualisation of attachment (Grossman 1985, Miyake 1985, Hindley 1993).

In sum, several studies have focussed on parent-child attachment and have concluded that it is compromised in the case of deaf-hearing children as compared to Deaf-Deaf children A compromised attachment is postulated to be related to negative psycho-emotional development In particularly this latter assumption, which is paramount to the argument of many who support Deaf culture submersion, has not been proven sufficiently in the context of deafness

Cognitive achievement

Cognitive and academic achievement are other issues that have attracted attention from the scientific community In general it has been shown that deaf children lag several years behind their hearing peers In the early twentieth century Pintner found a sample of 2172 deaf children to lag behind approximately two years, in spite of "average" performance on non-verbal tests (Pintner 1920, Paul 1993) Later studies report that most deaf adolescents lag behind at least 9 to 10 years in their reading and writing skills, which are considered essential in determining career opportunities (Paul 1993, Conrad 1979, Hindley 1993) The Gallaudet Research Institute found similar numbers on English reading comprehension based on the widely used (in the USA) Stanford Achievement Test (SAT) the median of the sample of 17 and 18 year old deaf and hard of hearing high school students corresponded to grade 4 (or age 10) for hearing students (Gallaudet Research Institute, 1996) Quigley also reports similar results the average 15-year-old deaf student performs at the level of a 9-year-old hearing peer (Quigley 1986) According to the US Centre for Assessment and Demographic Studies (1991) only 3% of deaf adolescents performed on par with their hearing peers It should be noted however that the comparative use of such plain data is contested, as it is believed to under-rate the potential of the deaf student Clements claims that up to one third of all deaf people are functionally illiterate (Clements 1986) A problem with many of these studies is that they have operated a cross-sectional methodology mostly, thereby possibly losing successful oral children (who are more likely to be mainstreamed) to the follow-up (Geers & Moog 1989) A second problem is that many studies were performed at a relatively young age, therefore missing possible *catching-up* that could occur later on Finally studies have failed to account for the impact of other disabilities that have influence on cognition, neurological disabilities in particular (Zwirecki 1976)

One of the main explanations of the abovementioned findings has been the thesis of sensory or language deprivation deaf-hearing children are deprived from language in their early years at home and continue to be relatively deprived if they attend an oral school Again, the viability of this explanation is a deduction based on the Deaf-Deaf paradigm Indeed Deaf-Deaf children appear to outperform deaf-hearing children in cognitive achievement terms (Sisco 1980, Ray 1982, Paul 1993, Stevenson 1964, Tellings 1995, Bonvillian 1973, Brasel 1977, Charrow 1976, Charrow 1974) Vocabulary, spellings, reading and writing skills all appear to be better in Deaf-Deaf

students even though not all studies confirm this (Parasnis 1983) Others, such as Geers, feel that the low achievement of deaf-hearing students is not so much the result of a poor language environment but rather symptomatic of *poor education* (Geers 1989) Indeed some students in intensive oral programmes appear to perform better (Paul 1993, Geers 1989, Tellings 1995). Geers and Moog, associated with two of the most famous oral schools for the deaf in the United States (Central Institute for the Deaf and the Moog School), report average readings skills of 100 orally schooled deaf students (biased by a relatively high SES) in the age of 15-18 to be similar to 14-year-old hearing students (Geers 1989). Furthermore they report that one third of their sample functioned more or less on par with hearing students

In concordance with the above, some authors believe that early enhancement of Sign language as a first language (L1) can safeguard cognitive development and may assist in developing reading and writing skills later on (Johnson 1989, Paul 1993) The first conviction is based on the fact that Sign language is an easier language to learn for deaf youngsters, therefore allowing them rapid access to language and as such access to a system through which they can acquire knowledge (Finnegan 1992).

> Early access to comprehensible language fosters early cognitive development which, in turn, promotes increased literacy and greater academic achievement (Baker 1997)

The second theoretical belief, based on second-language studies in hearing bilingual settings, has led to "bilingual programs" where the spoken language (mostly in its written form) is taught as a second language (L2)

> The emphasis on early language acquisition and establishing a first language (ASL) provides a base upon which English is subsequently taught (Baker 1997)

Convincing empirical evidence for both theses is largely lacking as of today, in part because of the young age of most of these programs, and some fundamental theoretical questions - such as the question if bilingualism is developed simultaneously or successively - remain controversial (Steinberg 1982, Paul 1993; Tellings 1995). Paul as well as others dispute the assumption that Sign language *alone* can succeed in promoting deaf students' literacy (Perfetti 2000, Stewart 1998) One of the main reasons being that command of "the language of reading and the associated culture is important prior to beginning reading activities", "reading is not merely language by eye" (Paul 1993, Perfetti 2000). Furthermore Paul states that, "there is no compelling evidence that first- or second-language learners achieve high levels of literacy through exposure to the written form only of the target language". Both statements appear to support the thesis that only those bilingual programs that employ a "maintenance" approach, which implies true immersion in L2 and equal attention to and valuing of L1 and L2, can be expected to achieve L1 and L2 proficiency Indeed maintaining the home language casu quo spoken language as L1 has been discussed as an alternative mode of BiBi education (LaSasso

1998). Neither the much discussed Swedish model - bilingualism has been affirmed by Swedish law since 1981 (Mahshie 1995) - nor the current bilingual programs in The Netherlands (Guyot, Amman) seem to comply to these criteria. Nonetheless the bilingual-bicultural approach is highly popular, likely in part as the result of its global non-empirical appeal which can be read from Finnegan's definition: "A person who is bicultural can move freely and between two different cultures. Biculturalism implies an understanding of the mores, customs, practices, and expectations of members of a cultural group and the ability to adapt to their expectations" (Finnegan 1992). However, the imposing question remains *if* these high standards can be achieved through the proposed bilingual programs for the deaf.

In sum, many studies have shown that the vast majority of deaf students lag behind their hearing peers significantly in terms of cognitive achievement in spite of the fact that their intelligence distribution is about similar. Even though the exact degree of backwardness is unclear and debated, it is likely to be in terms of years rather than months. These data are often perceived in support of the language-deprivation thesis since Deaf-Deaf children apparently do better. As such these data have been perceived as a support for early Sign language submersion and bilingual programs. While a Sign-based education may safeguard general language development, it is unclear if spoken language skills are sacrificed or not. Yet some oral-aural educators feel that it is inadequate oral-aural training rather than the oral-aural approach in itself which is to blame.

Educational attainment

Educational attainment can be expressed in terms of *outcome* and in terms of *process* (Dandermark 1995). The first focuses on achievement in terms of educational level, grades and standardized test scores and overlaps with cognitive development to some degree while the latter is preoccupied with the social and emotional embedding of the educational experience (social acceptance, communication ease, classroom engagement, self-esteem). As we discussed under cognitive achievement, many empirical studies have scrutinized the development of deaf students in terms of reading and writing skills as well as standardized (mostly verbal) test performance. Yet little is known beyond this. Secondary education is important in itself, in the sense that it contributes to self-development, yet it is also of value in its capacity to prepare adolescents for post-secondary education and, ultimately, career opportunities. How many deaf students actually succeed at college-preparatory and college level and what career opportunities are at their disposal? The available data on these issues is surprisingly limited.

McLoughin found that only one-third of all deaf Americans complete high-school (McLoughin 1982). Reporting on a large sample (n = 1893) Barnartt reports that only 12% of male and 10% of female deaf students enroll in post-secondary education

(Barnartt 1985). Vernon tracked 57 "gifted" deaf and hard of hearing students longitudinally over a period of almost 4 decades (Vernon 1993). It was found that 43% of this sample completed post-secondary education at college level while 18% proceeded beyond that. Lane and Calvert have reported on the comprehensive alumni archive of one of the most famous oral schools for the deaf, the Central Institute for the Deaf (Lane & Calvert 1986). The results are potentially confounded by selection bias, most worrisome being the inclusion of alumni with hearing losses in the range of 60-90 dBHL (31.7%). Yet this problem is also applicable to the aforementioned Gallaudet study. Even so the results may still provide some provisional idea of the cognitive outcome of a rigorous oral program. From 1914-1969 60.5% of CID alumni transferred to mainstream education, a number that was fairly constant over the years. Those mainstreamed were about 2-3 years behind their hearing peers in educational terms. Most of those transferred actually graduated (93.4%). About 16.8% transferred to a program for the hearing impaired and the fate of 22.7% was unknown. Students transferring to a high school for the hearing impaired had lower success rates in terms of graduating (66.4% versus 86.4%). A Dutch study of IvD alumni from 1960-1989 (n = 830) revealed that 13.4% completed post-secondary education at the (junior) college or university level (Diemer 1992). Confounders of educational achievement include SES, age of deafness, degree of deafness, spoken language proficiency and school type (Schroedel 1987). Schroedel as well as Dandermark found that students who did not attend special education were more likely to succeed, yet this factor may also confound for degree of deafness etcetera (Dandermark 1995).

The educational level attained by the average deaf person is considerably lower than in the hearing population, even though average IQ-scores are said to be rather similar (Holt 1994). As is the case with the previously mentioned cognitive achievement, the oral regime has been held accountable for this. Yet little is known about the merits of sign based education in terms of outcomes on the longer run, in part as the result of the fairly recent introduction of this type of education. It is not entirely clear if the vindication of the oral regime is legitimate or not since other risk factors for underachievement can be pointed out. The educational *quality* has never been assessed in an encompassing way. Though IQ is said to be on par, co-morbidity is high and may play a negative role if data are clustered. Limited access to colleges and universities may also reduce outcome. Furthermore it has been suggested that deaf schools have the tendency to educationally prepare their students for vocational low-skilled or manual jobs (Hollman-Borsjé 1990). In their seminal Dutch study, Breed and Swaams-Joha found that almost half of their adult respondents learned a trade in deaf school (Breed 1986). Ambitions of deaf students have also been reported to be low (Rodda 1970). These factors will likely also influence the outcome of Sign language schooled adolescents.

In sum, in terms of outcome deaf students generally achieve considerably lower levels of education compared to hearing peers. The high-threshold oral approach has been blamed for this finding. Yet it has not been demonstrated that there is a causal

relationship between oral language and educational achievement Alumni of some oral schools appear to do rather well in educational terms Moreover it has not been shown that sign-based education can actually overcome this deficiency

Societal functioning

Little is known about the societal functioning of deaf adults We find this surprising, since the adult situation comprises an important parameter in any deliberation A landmark American study in this respect was published by Schein and Delk (Schein 1974) The authors report that SES amongst the deaf is considerably lower than in the normal population De Graaf and Bijl report that 50 3% of their Dutch adult deaf and hard of hearing sample (n = 523) was employed, 35 6% full time and 14 7% part-time (De Graaf 1998) In 1999 the general unemployment rate in The Netherlands was about 4%, hence implying a 12-fold difference (CBS data) The authors warn however that these numbers may draw an optimistic picture since it is likely that the recruitment method favored those with a higher education Hommes feels that the incidence of unemployment is comparable to people with a moderate to severe physical disability (Hommes 1997)

A 1999 survey by the Canadian Association of the Deaf revealed an unemployment rate of 37 5% while an additional 41 9% was found to be "underemployed" compared to 8 1% and 31% respectively in the general population (Nichols 1999) Larisgoitia reports on 175 deaf adults in Pennsylvania and found an unemployment rate of nearly 40% (Larisgoitia 1997) Vernon reports on 57 "gifted" deaf and hard of hearing adults in the United States and mentions a 30% unemployment rate in spite of the fact that many attended some form of post high-school education (Vernon 1993) Schildroth examined the occupational position of the deaf population in the United States (Schildroth 1991) Again these numbers point towards a large employment backlog One of the largest samples available is the US National Longitudinal Transition Study The 1995 version of this study revealed an unemployment rate of 75 2% for deaf adults who had left secondary special education for up to three years The hard of hearing did better with 56 6% (US Department of Education 1995) The attendance of postsecondary academic education was 28 3% while 19 9% attended vocational education ("beroepsopleiding") For the hard of hearing these numbers were 35% and 20% respectively

As can be expected based on educational data, deaf people who succeed in the workplace often do so in vocational or low-skilled jobs (Hollman-Borsje 1990) Allen mentions office jobs, computer related jobs, domestic jobs, construction jobs and food preparation jobs as being the most prevalent (Allen 1989) In a study of culturally Deaf Norwegian individuals, Olsholt et al found that half of their respondents did simple manual labor or worked in furniture repair, as a shoemaker or dressmaker (Olshof 1988) Of deaf students who *do* attain a professional degree, a majority (77%) works in the deaf

sector itself (Crammatte 1987) In an analysis of Gallaudet University graduates, Armstrong presents rather favorable data (Armstrong 1983) Graduates were more successful in obtaining jobs as compared to non-graduates full-time jobs were held by 73% of graduates and 54% of non-graduates Furthermore, the chance of working in a professional sector was far better for graduates 85% for graduates versus 21%-30% for non-graduates The majority of professional graduates work in deaf education 65% of males and 80% of females

Income of deaf people is considerably lower than in the hearing population (Holt 1994) Barnartt found that in 1976 American deaf women earned only 60% of the wages of hearing women (Barnartt 1985) In Norway, Olshof reports that two thirds of their respondents earned less than the average income (Hollman-Borsje 1990) Income perspective is related to the degree of hearing loss (Mowry 1987)

Educational achievement is an important confounder of societal success (Bonnema 1977) The level of spoken language proficiency is of importance as well, but this may be through bettering the chances of education primarily McCartney found that members of the Oral Deaf Adults Section generally attain a good education and have a favorable societal outlook, even though his study suffers from a low response rate (McCartney 1987) Bonnema found that spoken language proficiency assisted the deaf and hard of hearing worker in succeeding in the view of employers (Bonnema 1977) Welsh found that educational attainment explained 34% of the variance in societal terms of NTID graduates (Welsh 1982)

While it remains difficult to draw hard conclusions from these data - since definitions of deafness often remain implicit hence possibly mixing deaf and hard of hearing data and recruitment-bias may occur such as in the study by De Graaf - it does appear that deaf adults are generally under-schooled as well as at great risk of unemployment From the titles available in literature it appears that, in accordance with the direction of disability advocacy in general (see for example van Wijnen 1997), the primary explanation has been socio-political which explains the abundant attention to issues such as employer-attitude, affirmative action and anti-discrimination laws (ADA in the USA, Wet Arbeid Gehandicapte Werknemers in The Netherlands) and training programs and job coaches (Krupnick 1976, Hommes 1997)

In sum, like educational achievement, labor participation and SES is relatively low in the adult deaf population The unemployment rate is likely at least 40-50% Many of those who have a job are underemployed vocational and low-skilled jobs are very common Deaf adults that master spoken language seem to be doing better in these terms

Conclusions

To draw general conclusions from the empirical data available is not an easy task because of serious methodological deficiencies. As we have shown, the results of these studies are rarely unanimous. Additionally, definitions, population characteristics such as cause and degree of hearing loss, SES and possible additional handicaps, operationalisation and instruments as well as informants (teachers, parents) are rarely homogenous (Broesterhuizen 1992). Also, many empirical studies lack power as they rely on a rather small sample. Correction for possible confounding effects is not always employed rigorously. Finally the merits of alternatives have not been evaluated thoroughly.

In spite of this, Deaf culture advocacy relies strongly on these empirical data or the *interpretation* of the data. The socio-cultural-linguistic reality of the deaf adult population is commonly depicted as strongly orientated at Deaf culture and Sign language and this reality often appears to be presented as "preference" rather than "fate". Additionally, the psycho-emotional data are often interpreted as proof of the unacceptability of spoken language and mainstreaming standards. Finally the cognitive-educational backwardness of deaf adults is commonly explained in terms of the oral regime that dominated deaf education up to the early 1970s. Yet we stated that some of these empirical "facts" have been exaggerated while none of the assumptions derived from the data have been empirically validated. Regarding the first, the socio-cultural-linguistic reality of the adult deaf population is far more diverse than depicted. While a majority of deaf adults indeed spends most of their time socializing with deaf peer, many of them *also* engage in hearing society and value these contacts. The same is true for Sign language: for many deaf adults manual-based language is the prime mode of communication yet this does not *exclude* spoken language. Regarding the second it seems that the hypothesis derived from empirical data are weak to say the least. Hence there is no convincing proof that psychiatric morbidity, low self-concept, deficient parent-child attachment, backward cognitive development and educational-societal achievement are *causally* related to any factor, including the oral regime.

This lack of evidence implies, we feel, prudence in overturning deaf education in the direction of Deaf culture too quickly. It is unlikely that such a strategy will correct the many problems that deaf people face, as much as it is unlikely that an exclusive oral axiom will. It may well be that the problems that have been elicited are only partially products of the education axiom of choice in itself and it may therefore well prove that many of these problems are rather *unwilling* vis-à-vis our educational interventions. This implies we feel, that we cannot refrain from examining the liabilities of our educational strategies beyond the issues discussed here. It is precisely this which Deaf culture advocacy has done: based on the hypothetical assumptions discussed, Deaf advocacy has prematurely rendered the potential fallacies of its own strategy default (Bertling 1998). Oralism has been declared the single and paramount "evil" of deaf education without

much prudence or nuance. While this attitude may trigger sympathy since at least it has been historically established that this specific mode of education failed to correct the situation of deaf people (which may facilitate "experimentation" with other modes of education), it is more difficult to sympathize with the resistance that surfaced at the introduction of cochlear implants. The merits of cochlear implantation were unknown to many of these opponents, yet this did not appear to temper their rejection. As such the resistance against cochlear implantation seems to represent the zenith of the anti-oral thesis.

SHORT HISTORY OF COCHLEAR IMPLANTS

General history

The first report regarding the sensation of sound triggered by extrinsic electric stimulation has been accredited to Volta (Hinderink 2001) While some of Volta's contemporaries did refine his rather crude and dangerous experiment, he placed a 50 Volt electrode in his ear, these early endeavors did not lead to any tangible results A genuine breakthrough did not occur until the mid-twentieth century when Frenchmen Dijourno and Eyries drew scientific attention to the possibilities of electric stimulation of the inner ear, which they performed during an otologic procedure for cholesteatoma eradication (Dijourno 1957) Dijourno and Eyries reported that it was indeed possible to recognize sounds through direct electric stimulation of the inner ear Some years after the publication of this case-report several established otologic research groups were drawn to the field the pioneering efforts of scientists such as House, Simmons, and Clark would prove to be momentous in the development of cochlear implant technology (Van Den Broek 1999) The House group is widely accredited for performing the first permanent cochlear implantation in 1962

Corresponding with the paradigm shift in medicine towards Evidence Based Medicine, clinical trials with cochlear implants did not start until the late 1970s The initial devices tested in a clinical setting were so called "single channel" designs In brief this implies that digitally transduced sound is presented to the cochlea through an electrode coding for *all* frequencies Notwithstanding the early date of implantation, the response of the scientific otologic community was lukewarm or even sceptical (Simmons 1985) A turn-around occurred with the publication of the Bilger Report in 1977, which presented the results of thirteen implanted post-lingually deaf adults and which had a positive impact on the acceptation of cochlear implantation as a feasible technology (Bilger 1977) By the mid 1980s the single channel House/3M device was challenged increasingly by multi-channel devices These latter devices attempted to anatomize the incoming sound signal into its constituting frequency bands, offering different frequency bands at separate loci on the intra-cochlear electrode, thereby imitating the natural function of the inner ear more closely At least theoretically this approach appeared promising, yet at first empirical proof was lacking Nonetheless the introduction of multichannel devices gave rise to a petty controversy as House and advocates of the multi-channel design exchanged their views in leading otologic journals (House 1995, Cohen 1995a) While House upheld his view that single-channel devices were as good or even better than multi-channel models, his single-channel concept eventually did not appear to stand up to the increasingly better results of multichannel implants

In 1984 the National Institutes of Health and FDA approved the cochlear implant for clinical application in post-lingual deafness By 1990, health authorities in many

industrialized countries had approved cochlear implantation for late deafened adults and - under some conditions - prelingually deafened children Today more than 40 000 deaf individuals have received a cochlear implant, of which nearly half are pre-lingually deaf children A few centers have developed into leaders in the field, being responsible for a large number of implant procedures the Universities of Iowa (Gantz), St Louis (Miyamoto), Miami (Balkany) and New York (Cohen) in the USA, the University of Nottingham (O'Donoghue) in the UK and the University of Hannover (Lenarz) in Germany

The first implantation procedure in The Netherlands was performed in Utrecht in 1985, followed by Nijmegen in 1987 Initially implantation in adults was restricted to a government sponsored study (n = 20), the results of which were reported in 1991 (van den Broek 1991) This study was followed by a second multicenter (Nijmegen and Utrecht) study in which 40 adults were fitted a cochlear implant, the results of which were published in 1995 (van den Broek 1995) Triggered by the positive findings in adults and the favorable reports by other implant groups, a study was conducted from 1993-1996 pertaining to the implantation of 20 deaf children (van den Broek 1996)

Determined to avoid the kind of polarisation between implant teams and the Deaf community which occurred elsewhere, Dutch otolaryngologist Van den Broek, sociologist and father of two deaf children Blume and deaf physician Govers, stimulated dialogue between implant teams and the Deaf community early on through the establishment of the "Cochlear Implant Platform", a unique initiative from an international point of view The platform joined surgeons and audiologists with leaders of the deaf and hard-of-hearing communities as well as representatives of parent groups The stake was an open exchange of views primarily but eventually developed into consensus efforts Even though the results of clinical studies were comparable to those reported by programs abroad and notwithstanding the remarkable initiative of the Cochlear Implant Platform as well as the positive recommendation made by the Dutch Health Council, the Dutch minister of Health initially did not authorize pediatric cochlear implantation as a regular health provision Rather she called for further research into the socio-emotional consequences of the procedure, responding to the critique of Deaf interest groups and some hearing sceptics For some time the resultant uncertainty seriously threatened the continuation of cochlear implantation in The Netherlands Finally, at the conclusion of 1999, the Dutch minister of Health approved cochlear implantation for pre-lingually deaf children By the end of 2000 over 100 children had received a cochlear implant at the AZN-IvD implant centre

The rationale of cochlear implantation

As explained previously, the philosophy behind cochlear implants is founded on the pathophysiologic premisse that the defect in sensorineural deafness is mostly located at

the level of the inner ear haircells, which makes intervention at that level a rational choice. Yet, the rationale of cochlear implants extends beyond this scientific paradigm alone. As we explained in the previous outline of deaf history, the education of deaf children has emphasized oral skills for many decades. This practice resulted in a large body of experience. One of the things deaf educators learned through experience was that the actual success of deaf children in terms of succeeding in an oral program varied widely: while some children succeeded others failed miserably. The severity of hearing loss proved to be a strong predictor of success: children with moderate to severe hearing losses generally are much more likely to attain usable levels of spoken language as compared to children with profound deafness. It is said that of those with profound losses only about 10% finally acquire such skills (Geers, personal communication). This experience has led to a popular classification: children with thresholds of 90-100 dBHL are referred to as "gold hearing-aid users", children with thresholds of 100-110 dBHL as "silver hearing-aid users" and children with thresholds beyond 110 dBHL as "bronze hearing-aid users" (Summerfield 1995). It has been demonstrated that at age 13 gold and silver hearing-aid users are quite successful in terms of spoken language skills, with speech intelligibility scores (untrained listeners) of up to 80% (Tait 1994). With the introduction of cochlear implants deaf educators hoped to improve the fate of deaf children from an oral perspective, in particular the fate of children with profound hearing loss or "bronze" hearing-aid users. Indeed Osberger and Snik reported that cochlear implants are able to achieve this: implanted profoundly deaf children were functionally comparable to non-implanted golden and silver hearing-aid users (Osberger 1993a; Snik 1997a).

Indication scope of pediatric cochlear implantation

By current standards cochlear implants are indicated for a number of profoundly deaf children. The decisive element in the decision is the expected benefit a child will experience from an implant in terms of spoken language acquisition. Since cochlear implantation is a new technology of unknown long-term efficacy that requires surgery, it must offer an individual child a definite edge over the available non-operative alternative of proven efficacy, namely conventional hearing aids. Deaf children are, as we discussed previously, at considerable risk of co-morbidity, particularly those suffering from acquired forms of deafness. In the case of acquired deafness, the causative agent - often an infection - may have inflicted additional damage to vulnerable organ systems such as particularly the central nervous system and cochlea. Additional handicaps may compromise the opportunity of cochlear implants to succeed in terms of spoken language acquisition. Additional handicaps may also have an additive negative effect on the emotional resilience of a child and as such may lower the range within which rehabilitation can be safely offered, that is without overly frustrating the child. Finally, a deaf child may experience significant gains in his or her access to sound, yet may still be unable to overcome the remaining communicative handicap. Perhaps also interesting in

this context is the issue of social environment, an issue which sparks controversy. To cash in on the theoretical opportunity that a cochlear implant provides, oral training will need to follow. A deaf child with a cochlear implant is still severely handicapped and cannot be expected to acquire spoken language skills naturally as a hearing child does. This implies that the socio-educational environment in which the child resides must be both able and motivated to provide in this respect (Deggouj 1998). If a child attends an educational program in which communication proceeds through manual language and no or very little opportunity for oral training is provided, one may question how realistic expectations of oral language development are and therefore question the suitability of an implant for such a child. Indeed Deggouj and others have argued that an exclusive sign environment is not recommended in a child with a cochlear implant (Deggouj 1998). Nonetheless a survey by Archbold revealed that 23% of implanted children in Europe are attending such programs (Archbold 1997). In the Netherlands this percentage may be even be higher, at least at the time when this study commenced: of 5 schools for the deaf in The Netherlands, four offer little training in spoken language. It appears that the emergence of children with a cochlear implant at these schools has not induced a change in policy. This has led implant teams to consider or reconsider the suitability of such children for cochlear implantation. Because the value of Sign language for deaf children is generally recognized, because schools are granted time to adjust their programs, because of the lack of convincing empirical evidence revealing inadequate performance of pupils of these schools and because of the desire not to polarize the issue, most implant teams have not excluded these children from their programs. Nonetheless the issue remains one of the most vital and controversial in the indication debate. In conclusion most cochlear implant programs consider the following criteria in determining indication: 1) sensorineural hearing loss of at least 100 dBHL in the best ear (lower hearing thresholds are a definitive trend however), 2) no serious co-morbidity and 3) the availability of at least a bilingual educational setting.

Review of Technology Assessment

Though exact numbers are lacking, it is estimated that world wide about 22,000 deaf children have been fitted a cochlear implant since it became available in the late 1980s. By 1999 about 110 pre-lingually deaf children were implanted in the Netherlands. The implementation of the procedure has been accompanied by many Technology Assessment studies (TA's). One of the main problems in discussing the results of these studies is that because of the low incidence of deafness, most cohorts are rather small in number therefore limiting statistical power. While meta-analysis may overcome this, the main pitfall of this strategy is very relevant for cochlear implantation indeed: variation in nomenclature, indication standards and population characteristics and inconsistent choice of instruments by different implant teams. One of the problems with the design of many studies is that they do not discount for maturation or time-effects. To establish this, one would have to design a case-control study or obtain standardized developmental curves.

A case-control design is not necessarily a solution however, since one of the main problems in the context of deaf children will likely be the selection of controls, given the wide range of variability (Truy 1998)

Nevertheless several authors have attempted case-control designs Truy and colleagues found that the developmental slope of receptive language abilities in implanted children significantly exceeded that of non-implanted deaf controls (Truy 1998) In addition Truy found that the post-operative developmental curves of implanted children were characterized by a coefficient change, indicating a specific effect of the implant rather than a selection bias in favor of the implanted group - one of the legitimate concerns raised by some sceptics Geers et al at CID compared implanted children with deaf controls using conventional hearing aids and found the former group to outperform the latter (Geers 1997) Interesting about the CID study is that both cases and controls were enrolled in the CID program, thereby eliminating the suggestion of post-implant educational bias Eilers and colleagues however report no differences between implanted children and controls with a hearing aid plus tactile aid (Eilers 1997)

The efficacy of pediatric cochlear implantation has been measured through several methods Most studies so far have focussed on the audiometric gains in terms of hearing thresholds after cochlear implantation More recently studies have been focussing more strongly on language development, educational placement, social skills, psycho-emotional strain and parental evaluation The next box summarizes some of the instruments utilized in cochlear implant TA's

Methods employed to measure CI effect

- Audiometric functional gain
- Speech recognition
- Language acquisition
- Educational placement
- Social skills & speech intelligibility
- Psycho-emotional functioning
- Self-evaluation by parents

Audiometric functional gain

It has been well established that cochlear implants yield significant audiometric gain for the average profoundly deaf child While the baseline audiograms typically reveal hearing loss with pure tone thresholds of 100-110 (but mostly over 110 dBHL) in frequencies over 500 Hz (speech frequencies) in the best ear (Staller 1991a, van den Broek 1996), after cochlear implantation the sound detection threshold improves to about 40-60 dBHL in most children (Snik 1997a), which is comparable to the threshold of children with moderate to severe hearing loss fitted with hearing aids (van den Borne 1999, Boothroyd 1997, Geers 1997, Snik 1997a)

Speech recognition

Improvement in recognition of monosyllabic words after cochlear implantation has also been well documented Summerfield and Marschall (1995) report on 142 children and found that pre-implantation 12% were able to identify words from small closed sets occasionally or consistently or were able to identify some words from an open-set format while this number increased to 80% post-implantation In another cohort Osberger found that 61% of implanted children achieved some open-set abilities (Osberger 1991) O'Donoghue and others have reported on the open- and closed-set speech perception abilities of the Nottingham cohort (n=119) prospectively (O'Donoghue 1998) It was found that closed-set speech recognition improved rapidly after implantation, reaching a score of 99% after 36 months Open-set speech recognition improved as well, albeit more delayed (O'Donoghue 1998) Similar results of slower developing open-set speech recognition, have also been reported by Tyler (Tyler 1997) It therefore appears that final outcomes of open-set speech recognition are subject to a learning curve that is protracted over several years Similar findings have been reported from the AZN-IvD cohort (Snik 1997a) Open- and closed set speech recognition results do indicate large inter-individual variability (Tyler 1997) The data may be argued to suggest that the prime gain cochlear implants provide is the availability of additional information cues rather than speech reception an sich To understand speech, deaf children rely on information cues such as the lip picture and context Cochlear implants add acoustic information to this set of cues One may question the significance of open-set testing in evaluating the practical merits of cochlear implants The fact that many implanted children do not attain open-set speech recognition anywhere near 100% cannot a priori be taken as a measure of the efficacy of the device It seems that the efficacy of the device should be measured in the ability of the implanted child to actually engage in oral communication Certainly, a 100% score on open-set speech discrimination is likely synonymous to a *vastly* improved ability to engage in such communication Yet sub-optimal scores may still yield significant improvement of this ability over the pre-implant situation In a one-on-one situation a deaf child will never depend on auditive information alone

Language acquisition

As we will discuss in more detail in chapter 8, one of the main critiques on cochlear implant TA's has been aimed at the choice of their instruments Psycholinguists feel that language-cognitive development rather than open-set speech recognition should be the key instrument (Szagun 1997) Implanted children may be able to talk, but can they think, feel and socialize (Robbins 1997)? Lane and others seem to feel that this cannot be the case, that the best that can be realized is teaching the deaf "sham speech" since "real speech is never taught, it is acquired natively at an early age and remains fluent for a lifetime" (Lane 1984) In depth psycho-linguistic analysis of language development is a time consuming activity that does not seem to match with the rather pragmatic orientation of implant teams, the large number of children implanted nor the resources available This explains in part why information on language development of implanted children is rather scarce and casuistic and does not allow final conclusions

There have been some studies however which employed the well standardized *Reynell Developmental Language Scale*. This scale is different from open- and closed-set measures in that it represents a developmental model of language. One of the most cited studies employing this scale was reported on by Robbins (Robbins 1997). Based on cross-sectional language data provided by 89 deaf controls Robbins concludes, through regression on age, that without an implant her cases were predicted to attain less than half of the language gain of normal hearing children. Using the control data as "normal" for deaf children, the pre-implant scores of implanted children were plotted on the normal to estimate their language gain 6 and 12 months after implantation. It was shown that 12 months after implantation, the implanted children (n=23) were 7 months ahead of their estimated language level. In addition the average language gain (coefficient) post-implantation was comparable to normal hearing children. Similar results have been found in other cohorts (Vermeulen 1999). Still, measures such as the Reynell are found deficient from a linguistic perspective. There have been only few studies employing a more profound analysis of language development in implanted children (Coerts 1998).

Educational placement

It is unlikely that a short-term study will detect changes in education placement of implanted children. Cochlear implantation is a process that takes several years and many implanted children still benefit from special education services in the years immediately after implantation. This perhaps explains why fairly little has been published about educational placement trends in implant populations. Recently several authors have reported on educational placement however (Francis 1999). Francis retrospectively compared 35 profoundly deaf children with a cochlear implant with 10 age-matched controls attending a TC program and reports a significant positive correlation between length of cochlear implant use and fulltime mainstream placement. After at least two years of implant use, the rate of attending mainstream education was twice that in the non-implant group. Vermeulen reports on the educational placement of 28 children from the AZN-IvD cohort who had been using their implant for at least 2 years (Vermeulen 1997). Prior to implantation 3.6% attended a regular school while two years after implantation this number had increased to 32%.

Social skills & speech intelligibility

While being able to comprehend what is being said comprises an important part of social interaction, so is of course the ability to express one's own experiences and ideas. Thus, if implants are to facilitate reciprocal communication, they would at least have to improve the intelligibility of spoken language to some extent. Miyamoto et al. studied the intelligibility of speech produced by implanted children compared to matched controls with hearing-aids, based on a panel-appraisals. It is concluded that implanted children outperform controls (Miyamoto 1997). Osberger and colleagues found that implanted children generally became comparable to good silver hearing-aid users in terms of their speech intelligibility three years post-implantation (Osberger 1993a). Allen and colleagues prospectively studied speech intelligibility in 84 pre-lingually deaf children up

to five years after cochlear implantation (Allen 1998). It was found that after five years the average subject was intelligible to "a listener with a little experience of deaf speech". However interesting the issue of language intelligibility, the ultimate test must be more pragmatic. Levy-Schiff (1985) has suggested that oral-aural skills will ultimately prove insufficient to allow reciprocal communication with hearing peers, resulting in social isolation. Few studies have attempted to address this issue empirically. It would seem that the quality or ease of communication in an oral-aural mode is related to how oral language is actually used by deaf children. Spencer and others compared 25 implanted children with 13 matched controls with a hearing aid (Spencer 1998). The group was invited to participate in a 12-minute session of spontaneous conversation. It is reported that the implanted children used the voice-only mode in 91%, while only 1% of the hearing aid group did.

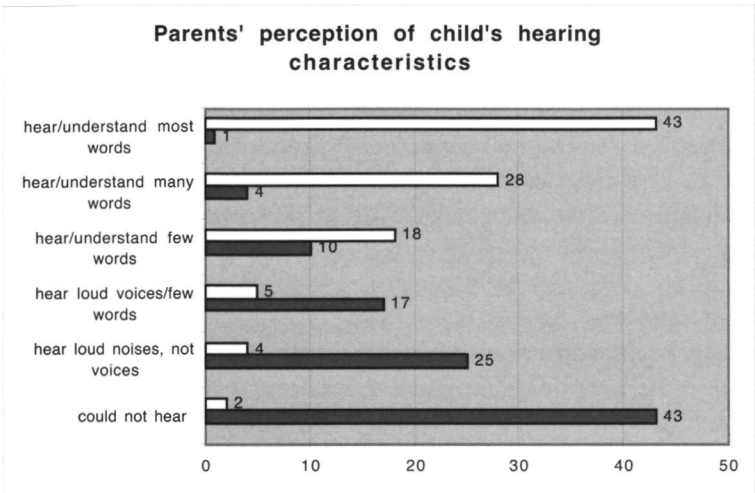
Psycho-emotional functioning

To date there has been little data available on the psycho-emotional consequences of cochlear implantation. Perhaps this is in part the result of the broad diversity of available concepts (psychiatric disturbance, self-image, self-esteem, loneliness, quality of life, identity, resilience, happiness) and instruments as well as - and perhaps more importantly - interpretive frames, an issue which we will address later. Ultimately many advocates of psycho-emotional research cross-refer to the concept of Self-esteem. Much identical to the early work performed by Meadow (Meadow 1968a), Stuckless & Birch (Stuckless 1966) and Myklebust (Myklebust 1960) the anticipated strain of cochlear implants is not considered specific to the procedure but alludes to the oral environment implants are foreseen to induce. If one desires to measure psycho-emotional strain in these terms it seems most suitable to do so after such an environment has come into place, which is likely to be many years after the actual implant procedure. In the AZN/IvD cohort, the Child Behavior Checklist (CBCL) as well as two other psychometric instruments were administered at baseline and at 12 months follow-up (van den Broek 1996). No evidence was found which would put implanted children at risk for psycho-emotional strain. Knutson also operationalized the CBCL as well as the HEQ and MCPS at baseline and compared results with non-implanted controls (Knutson 1997a). This study also confirms that implant candidates are rather similar to controls in psychological profile, at least at base-line.

Self-evaluation by parents

One of the most comprehensive self-evaluative studies so far was performed in the Nottingham cohort. Another study that must be mentioned in this context is the Gallaudet's parent survey (Christiansen, in press). Christiansen et al. found that 96% of their sample reported that their child was using the implant, therefore refuting the rumor that many children do not use their implant. While before implantation 68% of the parents reported that their child could not hear or only hear loud noises, after implantation 71% claimed that their child could hear and understand many or most

words. The figure below illustrates the result (in %, white bar is after cochlear implantation, black bar is before cochlear implantation).



Courtesy of Christiansen

After cochlear implantation use of spoken language increased in the home environment even though Sign language was still used "as support" by the majority of parents (62%) and 5% used Sign predominantly. Speech intelligibility was also reported to have improved. In terms of schooling, 38% of the implanted children were mainstreamed even though many still needed assistance of Sign language interpreters. Nikolopoulos also reports high parent (n = 43) satisfaction post implantation (Nikolopoulos 2001). Three years after implantation, 98% reported improvements in terms of communication with others, 88% reported improvements in terms of listening to speech without lipreading and 86% noted improvements in terms of speech and language development.

Confounders of cochlear implant results

Age of onset of deafness is an important factor in explaining result variance. Staller explains 25-49% of variance based on this factor alone (Staller 1991a). Indeed, post-lingually deaf individuals generally do better than the prelingual deaf (Gantz 1994). The fact that the pre-lingually deaf lack any auditory memory at all could explain this finding. Yet children who *acquired* deafness prelingually perform about the same as those born deaf (Miyamoto 1993, Gantz 1994, Summerfield 1995). The elapsed time between onset of deafness and implantation is also of influence (Staller 1991a, Miyamoto 1994, Dowell 1995). Again, this has been shown mostly in the rather extreme situation of implantation of the pre-lingually deaf after the age of 12 (Snik 1997b, Osberger 1993b). Furthermore these two factors may be interrelated as congenital deafness is often diagnosed more delayed than acquired deafness therefore extending the interval to cochlear implantation

(Snik 1997b). Rehabilitation content is also of influence on cochlear implant outcome. Several studies have revealed less favorable results if implanted children are rehabilitated in a signing or signing-orientated environment (Moog 1995, Snik 1997b, Osberger 1994). Surgical success in terms of electrode insertion has also attracted attention. Even though pre-operative CT scanning of the temporal bone is standard, surgeons are sometimes confronted with an ossified cochlea that does not allow full insertion of the implant electrode. It is generally assumed that such a partial insertion is a sub-optimal situation. Nonetheless some authors have concluded that a partial insertion need not compromise the outcome, though this remains controversial (Osberger 1994; Snik 1997b; Van den Borne 1999).

Surgical complications

The surgical complication rate in cochlear implant surgery is generally reported to be low and rather similar to that of an average surgical procedure (Luetje 1997; Gezondheidsraad 2001). The most serious surgical complication is facial nerve damage (Cohen 1994). Postoperative complications such as infection and necrosis are reported to occur in 3-5% of cases (Cohen 1997). Long-term complications are mostly unknown. Technical failure is reported to be 1-2% per year while the longevity of the implant itself is estimated to be 15 years (Gezondheidsraad 2001).

Conclusions

The history of cochlear implants dates back to the late 1950s. Initially the scientific community was somewhat sceptical about the potential of implant technology. This changed after the publication of the Bilger report in 1977. In 1984 the National Institutes of Health approved clinical implantation in post-lingually deaf adults and not long after the approval of implantation of pre-lingually deaf children followed. The aim of cochlear implants must be viewed in light of the historical finding that only very few profoundly deaf children ($\geq$ 110 dBHL) attain usable spoken language skills. The degree of hearing loss is inversely related to the chance that spoken language is acquired. It is hoped that the fate of children with losses in excess of 100-110 dBHL in particular can be improved with a cochlear implant. The indication criteria of cochlear implants are not universal and are shifting. At least initially children were selected based on criteria that were felt positively related to the chance that spoken language would develop. Hence, children were selected based on criteria such as normal intelligence, the lack of additional handicaps, a motivated home-front, and adequate spoken language stimulation. Notwithstanding this, most implant centres operate these criteria flexibly. In particular a predominantly manual educational environment, while being controversial, has not led to categorical exclusion by many implant teams. Cochlear implant assessment has mostly been based on rather heterogeneously composed small to medium sized series without the addition of controls, which compromises the validity of the results to some degree. Most studies have focussed on audiometric parameters and open and closed set speech

recognition. Both these parameters improve significantly after cochlear implantation. Based on the Reynell scale, several studies have also shown that language development is positively influenced by cochlear implantation even though some linguists feel that this scale is an inadequate measure of language. Regarding educational placement few data are available. This is at least partially explained by the fact that benefits of implantation continue to increase over a period of many years and the fact that most cohorts are still relatively young. From the data that are available it seems that cochlear implantation has a positive impact on mainstream educational placement. Speech intelligibility is also reported to improve after implantation: most implanted children are intelligible to a listener with some experience with deaf speech. Pragmatic skills, the skills required to actually engage in conversation with hearing peers, have not been studied widely either but there are indications that implanted children find it easier to engage in spoken language as compared to non-implanted peers. Psycho-emotional liabilities of cochlear implantation have not been studied intensively but it appears that, at least on short-term, these liabilities do not materialize. A growing number of studies focus on parent reports. Parents report definitive pre-post implant gains with up to 70% reporting that the child could understand "many" or "most" spoken words.

THE CONTROVERSY OVER COCHLEAR IMPLANTS

Introduction

The introduction of cochlear implants for pre-lingually deaf children has provoked broad opposition, mostly from the adult Deaf population (Gibson 1991, Rosen 1990, Berliner 1988, House 1986, Lane 1992). Most memorable in the minds of many European implant experts is perhaps the 1993 Paris conference on Pediatric Cochlear Implantation, which was disturbed by uninvited Deaf protest. The critique has been voiced by a relatively small group of spokespersons, most of whom are hearing. Most noteworthy in this context is Bostonian psychologist Lane who outlined his objections eloquently in his 1992 book The Mask of Benevolence (Lane 1992). Lane and others engaged in lengthy polemics with implant pioneers such as Balkany, Cohen and House in leading otolaryngological journals (Balkany 1993a/1993b/1995/1996; Cohen 1994b/1995b; Davis 1997; House 1986; Hyde 1995; Lane 1997; Miner 1996; Pollard 1993; Rose 1994/1996; Shea 1993; Govers 1995; Wever 1998).

To summarize the critique on pediatric cochlear implantation unreflectively is a difficult task. The reason for this being that 1) the critique is highly fragmented and often lacks a cohesive argumentative structure, 2) the critique has shifted or developed in time and 3) the critique often takes the form of a political rhetoric. The first point implies that it often is difficult to extract encompassing points of view since very few have presented their case in such a fashion. It also implies that it is often difficult to extract arguments from the critique, rather it often seems more suited to gather opinion from it. The second point implies that questions may arise as to the "true nature" of the critique since the critique itself shifted over time as proponents of cochlear implantation assembled their case. The third point implies that to allow the critique is to allow a very specific political position that has no undisputed authority in itself, an issue on which we will expand in chapter 7. All in all this situation implies that any summary of the critique on pediatric cochlear implantation is necessarily an interpretative effort.

The critique at pediatric cochlear implants will be discussed in depth in chapters 7 and 8, for now we will suffice with a brief summary of this critique. The National Association for the Deaf (NAD, USA) formulates her "scientific" critique at pediatric cochlear implantation as follows:

- there is no evidence that the speech perception of these children is materially enhanced
- there is evidence that many profoundly deaf children would have better...speech perception with conventional hearing aids than with implants
- there is no evidence that early-implanted children will do better at acquiring English than they would with non-invasive aids or no aids whatever.

NAD, Positional paper Cochlear Implants in Children 1993

Furthermore, the NAD proceeds beyond scrutiny on cochlear implant assessment trials by stating that

- there is no evidence that early-implanted children will have greater educational success
- programs are conducted without regard to the quality of life that the child will experience as a deaf adult implant user
- it is presently unknown whether the implant will delay the family's acceptance of the child's deafness and their acquisition of sign communication
- impact on socio-intellectual and emotional development and mental health or on the child's integration into the deaf community have not been assessed

NAD, Positional paper Cochlear Implants in Children 1993

This latter level of critique may be summarized as stating that spoken language attainment is too narrow a measure to determine the value of cochlear implantation Rather we should be concerned with the well-being of deaf children from a much broader perspective Spoken language attainment is considered only one part of this This critique has been widely adopted by other sceptics Govers feels that implant trials wrongfully equate speech perception to language (Govers 1994) Furthermore he feels that the circumstances under which speech perception have been measured have been too ideal, since noise is typically eliminated and investigators tend to articulate perfectly Indeed Katz has argued that if the environment more realistically includes noise, the success rate is likely to drop significantly (Katz 1994) Critics hence feel that many implanted children will *not* attain *usable* spoken language skills (Katz 1994) Moreover, the successes that have been reported by early assessment trials have been attributed to selection bias Rose comments that she was "struck by the almost cavalier fashion in which the results of congenitally and pre-lingually deafened children are combined with those of post-lingually deafened children" (Rose 1996) Critics also feel that, given the small samples and design of many studies, it has not been sufficiently established that cochlear implant results are not due to confounding by the intensive rehabilitation environment (Govers 1994)

Socio-historical background

To understand the critique on pediatric cochlear implantation necessitates an understanding of the position of the Deaf community at the time that implants found their way to the otolaryngological establishment This position was in part outlined in the previous section on the history of deaf education In sum, in the early 1980s the Deaf community in many Western countries had departed on an emancipation journey, supported by new insights into the position of Sign language and a cultural climate promoting civil rights This journey encompassed a different self-image, changing from a view of *failure* to conform to the hearing standard to a view of *pride* and *accomplishment* as signing Deaf individuals

Deaf individuals have repeatedly described how the climate in oral institutes for the deaf produce an injured self (Laborit 1994). With so much emphasis on oral language, it appears that many deaf pupils founded their self-image in their (in-)ability to achieve in this respect. Indeed in our contact with deaf people we found that even those individuals who pride themselves for their spoken language ability are exceedingly sensitive to negative judgements regarding that specific ability. In addition, it appears that in many instances the self-value created in deaf institutes failed the test once students left the safe environment of the institute (Van Noort 1999). Deaf individuals who prided themselves based on their institutional achievements often found a hostile world beyond its secluded boundaries: a world of people who failed to understand their spoken expressions, who failed to invest in them with patience, a world that failed to exhibit solidarity towards their unique situation and a world that turned away from them in forging friendships. In in-depth interviews with adult deaf individuals (a spin-off of this study), this negative experience was recounted by all respondents (Van Noort 1999). It takes little imagination to understand how such experiences may have led to scepticism towards the former deaf institute on the one hand and the hearing world on the other. As a result, many deaf individuals harbor resentment towards the deaf education that they enjoyed. On the one hand, the strong emphasis on spoken language is depicted. On the other hand, deaf schools are depicted of hypocrisy, creating self-images that failed the test terribly in the outside world. A second result is that many deaf individuals harbor resentment towards the hearing world, a world in which many were to be marginalized unwillingly. Many deaf individuals did find friendship, recognition and comfort in the domain of their local signing Deaf community. For many deaf individuals this community eventually became the only in which they could develop meaningful social relationships. In order to enjoy the benefits of this community however, deaf individuals had to do exactly what they had been told not to do for so many years: use Sign language and retreat from hearing society. It seems reasonable to assume that this shift in perspective requires quite some psycho-emotional *elasticity* or *narrative reconstruction.*

The gaining momentum of Sign language research and advocacy in the 1970s and 1980s reassured deaf individuals however, providing them with support in the sense of providing scientific legitimacy to their situation and experience. There was no reason to be ashamed of Sign language this research proclaimed and moreover, deafness was to be perceived as an "existential trait" through the distinctiveness of Sign language and Deaf culture, which legitimized the retreat into the Deaf community to some extent. Rather than perceiving of the Deaf community as a community of social failures, an "exit option" in words of Hirschman (Hirschman 1972), it was transformed into a proud minority community with its own language and cultural expressions. Much similar to the ethnic minority movement in the 1960s, the Deaf community started to identify itself with credos such as "Deaf pride" and initiated a search for unique cultural expressions. Political representation of this new Deaf awareness launched political campaigns demanding the recognition of Sign language as a minority language, the introduction of Sign language in deaf institutes, the involvement of the Deaf in political and educational

debates and lobbying for societal support of the Deaf case in terms of, for example, wide-spread subtitling and Sign translator availability.

It is in this dynamic social environment that cochlear implants found their way to the mainstream. Several factors likely added to the agitation surrounding their introduction. Firstly, implants were a medical-audiological procedure that may have triggered reminiscence to negative oral-aural experiences. Secondly, quite a few of the early implant programs "collaborated" with renowned oral institutes, such as the Institute for the Deaf in Sint Michielsgestel and the Central Institute for the Deaf in St. Louis - which had become a "wicked" symbol for many deaf individuals. Thirdly, the Deaf community was not involved in any way in the launching activities. Fourthly, the tone of the original public campaign pretty much nullified the newly acquired self-image. If the Deaf community was not to be perceived as one born out of need and failure but rather as a vital community with its own language and culture much like an ethnic community, how was it then that new generations of deaf individuals were to be implanted with the aim to master spoken language rather than Sign? It therefore seems that the resistance against pediatric cochlear implantation was at least in part procedural and emotional-narratological in nature. This implies on the one hand that it may not have necessarily required concrete resistance against the objectives of cochlear implantation, namely to better the ability of profoundly deaf individuals to access spoken language, but rather revolt against the way in which the technique was introduced. It implies on the other hand that the state of confusion surrounding the self-image of the Deaf community triggered by the cochlear implant was responsible for the resistance.

Sceptics

Nonetheless specific critique aimed at the premises and claims of pediatric cochlear implantation did arise. The most common form of critique by Deaf individuals was that of scepticism. In the Netherlands the title of Govers' (the country's only deaf physician) MA thesis exemplifies this scepticism: "New Ears of the Emperor: reality or illusion?" (Govers 1994). Drawing parallels to oral education of deaf children and the introduction of hearing-aids, Govers and others questioned if this new technology would indeed succeed in bettering the chances of deaf children to acquire spoken language skills significantly as it claimed. Even if it would, it would still be erroneous to believe that such an advantage would translate to "benefits" in real life (Govers 1995). Many have joined Govers in this scepticism. Blume for example, has drawn attention to the self-propelled trust of medical technology, arguing that there are a good many reasons to promote this new technology which are fully beyond the issue of the well-being of deaf children (Blume 1997). Since oral training is required to make cochlear implantation successful, fear was expressed that implanted children would be submitted to rigorous oral-aural programs much similar to those common before the 1970s, without leading to significant results ultimately - hence representing a lose-lose situation really. Much like

their adult deaf peers, implanted children would suffer emotionally from the rigorous demands placed on their fundamental inability without being able to ever actually advance in terms of spoken language (Govers 1995). Additionally it was feared that cochlear implantation would segregate deaf children from the Deaf community, a community to which some hold they "belong". Others stressed that since the implant will fail to provide the deaf a reasonable social alternative and since it would segregate the deaf from the Deaf community, social isolation and a "vagabond identity" or sense of non-belonging would be inevitable. To make things worse, the oral revalidation which cochlear implantation requires would cheat the deaf from resilience to deal with their challenging situation adequately, leaving a severely damaged person behind. In light of the highly optimistic tone of early implant campaigns in the public media, critics also feared that cochlear implantation would distract parents from their assignment to "accept" their child's deafness and to provide their child with the advantages of Sign language. Thus, cochlear implantation was feared to cater to parents looking for an *easy way out* so to say, something still heard today. Somewhat similarly, it was feared by some that governments would respond analogously. Though cochlear implantation is certainly an expensive technology, its costs fall short of the immense costs of special education and prolonged social dependency of deaf people. Hence, it was feared that governments would respond favorably to cochlear implantation yet would eventually cut on investments on special education and Sign language services. This latter fear has to our best knowledge never been expressed in formal writings yet can be abundantly heard in the informal circuit. Another fear that is rarely expressed formally is the potential impact of cochlear implantation on the composition of the Deaf community. Since implant teams were selecting implant candidates based on the absence of additional handicaps, perhaps intelligence and the motivational state of parents, it was feared this new technology would leave a weaker population behind to constitute the Deaf community.

Beyond scepticism

As it became clear that cochlear implants did indeed produce remarkable results in selected cases of profoundly deaf children, much of the initial resistance subsided to some degree. Today, the Dutch Deaf Federation as well as the Dutch Federation of Parents of Deaf Children both recognize the potential benefit cochlear implants may have for selected deaf children. Attention is now aimed mostly at increasing the quality of the implant procedure, which includes such central issues as selection criteria, the preferred revalidation strategy and the relationship of cochlear implants and Sign language. Scepticism has not dissipated nor has concern over the impact of cochlear implants on the Deaf community. Rather the attitude of the Dutch Deaf community today appears to be one of cautious-monitoring. Nonetheless the controversy continues in some circles. If one is familiar with Lane's work, one will readily understand that implant success in terms of spoken language acquisition does not satisfy his critique. As a matter of fact,

Lane has been quite clear about this in his scenario of "the perfect implant" which was discussed before In general, critics who renounce cochlear implants based on a civil rights discourse are unlikely to release their resistance based on positive spoken language findings

Conclusions

It is not easy to sort out the critique on cochlear implantation since this critique has been rhetorical in nature, fragmented and dynamic The socio-historical position of the Deaf community at the time when implants were introduced is critical for our understanding Since the 1970s the Deaf community has been in transition While many of today's adults attended an oral school for the deaf where they were taught that sign was an unwelcome mode of communication, the 1970s marked a shift towards Sign language The transition was by no means restricted to a change in language Rather it was accompanied by a more profound shift in discourse, which can best be labelled a civil rights discourse deafness was being projected as an existential cultural trait, those who insisted on oral language were being convicted vis-a-vis this discourse This shift in ideology was welcomed by many deaf adults who had experienced the failure of the oral promise In spite of years of effort most deaf students failed to achieve a level of oral language proficiency required to function in society at large In spite of intense efforts from their side, the goal of finding a place in hearing society often ran aground violently The new discourse supported deaf adults by blaming oral schools and hearing society for their suffering Yet only a few years later cochlear implants were introduced, often accompanied by much fanfare in the public media The semiotic denotation of these devices is much similar to that of oral schools, hence the critique was to be expected implants compromised the right to Sign language and Deaf culture Furthermore some deaf adults may have identified the hypocritical role of hearing society towards their fate the cultural model was abandoned as soon as an effective method to attain oral language was uncovered These factors in themselves explain why implants were dismissed so fiercely The specific arguments against cochlear implants have been diverse A main factor has been scepsis about the ability of implants to succeed Embroidering on this, it was feared that the implanted child would not succeed in hearing society while also failing to find a place in Deaf culture, leading to a "vagabond identity" A second argument has been the fear that success would inevitably induce emotional strain as the result of intensive rehabilitation Also heard is the argument that cochlear implants would play into parents' natural inclination to deny the handicap Less heard issues are the fear of a "brain drain" from Deaf culture and the damage implants could induce to Deaf culture as an interest group since intelligence may well be a modifier of cochlear implant success, implants could draw the smart kids away from Deaf culture If governments operate a fixed budget for deafness, investments in cochlear implantation may go at the cost of other services that benefit the signing community Finally there is the most

fundamental critique which returns to the civil rights discourse of the 1970s. From this perspective any effort to teach deaf children spoken language is reprehensible.

Towards the end of this study, the controversy surrounding pediatric implantation was subsiding considerably even though it is unclear whether this implies that the aforementioned objections have been withdrawn or that pragmatics explain the milder tone. In a recent article on cochlear implants in "Research at Gallaudet", formerly fierce opponents of cochlear implantation such as Bahan and Scott speak a much milder language (Johnson 2000). On the one hand it appears that 15 years of pediatric cochlear implantation has convinced them that the procedure does not threaten the Deaf community since "in many cases Sign language will continue to be needed as a communication option" (Johnson 2000). On the other hand there are some indications that the latter is the most likely explanation: Johnson explains the research cooperation of Gallaudet University with the Johns Hopkins cochlear implant team by mentioning the "present day reality that cochlear implants are here to stay" and "several Gallaudet students are already implanted" (Johnson 2000). Gallaudet's Graduate school Dean, Thomas Allen, adds that "In 8 or 9 years a considerably increased proportion of deaf prospective college students will have implants, so Gallaudet must be prepared to create an environment hospitable to such students" (Johnson 2000).

CHAPTER 2 – METHODOLOGICAL CONSIDERATIONS

POSITIONING THE ETHICAL PERSPECTIVE

Introduction

As outlined in the preface of this thesis, the main aim of this thesis is to provide an in depth view into the moral dimensions of pediatric cochlear implantation with an emphasis on the decisions parents have to make. Therefore, we have chosen semi-structured interviews with parents of deaf children as the main empirical source. In doing so it may be argued that we make specific choices from both a methodological as well as ethical point of view, at least in so far that we evidently consider the narratives of parents as indispensable in understanding the moral dimension of the cochlear implantation decision. Surely, it would have been possible to analyze the issue at hand without consulting parents. As a matter of fact most analyses so far have drawn on rather fragmented anecdotes. Notwithstanding this omission, many essayists do allow themselves the freedom to postulate far-reaching conclusions about parents and the morality of their decisions. While in the past parents who chose for an oral education for their deaf child were "consulted", this consultation was also rarely explorative in nature. Rather parents were subjected to fully developed empirical instruments with established frames of interpretation such as the "Attitude to Deafness Scale" (Hadadian 1991).

In analyzing the argumentative structure of Lane, one of the leading opponents of pediatric cochlear implantation, it appears as though a rather fixed moral frame is projected over the issue, which indeed seems to render further inquiry into the narratives of parents unnecessary. The key conviction is that the choice for a cochlear implant is morally unacceptable *because* deafness is an "existential trait", and because it is not bad or even good to be deaf. The reasons people may hold, have very little bearing on this evaluation. Ergo, the "morality" of cochlear implantation is located in the act itself, thereby making an inquiry into context and motives of less importance. Of course, there are reasons for this conviction yet it would seem that parents have their reasons too and it seems unlikely that these latter reasons can be indisputably read from the act itself. As Robinson explains:

> Intentions are a major determinant of behavior and meaning, but often cannot be unambiguously identified from behavior alone. [..] Behavior can be embedded in several plans operating over varied time spans and relationships. [...] Without further information an observer would not know which descriptions are valid or most salient. (Robinson 1996)

Not unlike Lane some advocates of cochlear implantation also seem to have assumed that the procedure is the only right decision one *can* take for a deaf child. As a matter of fact it is our experience that many, if not most, people who are unfamiliar with the controversy are bewildered to learn that some people actually oppose cochlear implantation (Foreman 2001). Their prime hidden assumption seems to be that deafness

is not a relevant category but rather a physical handicap that *must* be overcome. This assumption may just as well lead to the neglect of the stories parents have to tell since these narratives are assumed to be of little significance in determining the outcome of an ethical inquiry. Both positions are normative and depend little on neither parents' narratives nor the real-life situation of deaf children.

We consider the moral space of critics as well as advocates of cochlear implantation as well as their foundational approach as being deficient to some extent (Hare 1989). Indeed, it is our conviction that the fixed moral space in which they stand falls short in achieving an integration of the complexity of moral issues involved (Isarin 2002). By taking a position of non-inquiry, one clear effect is those alternative "reasons" which may lead to different conclusions do not see the light of day. It also implies that the "moral space" on which a judgment is based is explicitly not introduced into the inquiry, thereby giving way to a perpetual circle of which medicine has been convicted in the past (Wever 1996): the choice for cochlear implantation is morally wrong (or right)...because is has been concluded that cochlear implantation is wrong (or right). The utility of specific "reasons" or "moral intuitions" are not included in such an analysis (Hare 1988). For a more detailed discussion we refer to chapters 7 and 8 of this thesis.

Thus, our aim has been to allow parents to speak freely about their choice for or against cochlear implantation, by not presenting ourselves as moral agents in the dialogue and by stimulating parents not only to position themselves but also to develop their thoughts during the conversation. Avoiding the role of moral agent was not uncomplicated, as parents did appear to grope after our position in the matter. Consequently it has been our aim not to limit ourselves to a judgment on the *end-point* of parents' deliberations, but rather to explore the deliberations *themselves*. Obviously we believed that there was "something to be found" in that context, something not only of narrative value but ethical significance as well. Thus, our starting point was that parents have a story to tell and in addition, that this story reveals information that can be re-introduced into an ethical deliberation. This preference embraces a relatively young school in medical ethics. A short history of medical ethics may elicit how narrative ethics has grown in popularity in recent years.

The rise of medical ethics in the 1960s

Since the late 1960s ethics has become a strong force in medicine. Several trends should be considered in this context: the technological discourse of medicine, increased technological abilities to sustain life, iatrogenic injury and the "social revolution". It is generally assumed that as medical technology expanded at a rapid rate in the 1950s and 1960s, doctors figuratively speaking forgot for whom and for what purposes their technical abilities were developed. Medicine emerged more and more as an autonomous discipline, caught up in a perpetual circle of legitimization: what was feasible technically

was almost automatically considered ethical (Wever 1996) By the end of the 1960s social scientists began to question this paradigm Medicine had to be "re-minded" of its pledge to the well-being of individual patients rather than to the science of biomedicine since the two were not considered to be automatically synonymous (van den Berg 1969) Around the same time, it also became increasingly clear that medical treatments had distinct liabilities, most outspokenly in the case of iatrogenic injury (Illich 1995) Yet other developments, such as increased surgical abilities due to the development of general anesthesia, mechanical ventilation and the heart-lung machine, were also potentially at risk of inducing more harm than benefit Hippocratic ethics assumes a hierarchy of values in which the sustaining of biological life traditionally stands at the top (Widdershoven 2000) The abovementioned developments stretched the area between biological life and death however, creating a large gray zone full of controversy A strongly related development was the socio-cultural "revolution" that took place in the 1960s, which marked a revolt against "authoritarian institutions", such as religion and politics Medicine was also encapsulated in this social critique, given the paternalist implementation of Hippocratic ethics that dominated the medical practice in those days Citizens and patients demanded more autonomy and rejected physician paternalism fiercely As a consequence, physicians could no longer simply implement treatments based on the Hippocratic oath, but were strongly persuaded to engage in dialogue with their patients inform them, listen to their wishes and desires and allow them to decide ultimately or at least participate in the decision (Widdershoven 2000) In general, medicine was persuaded to re-think its technology in terms of the subject or the patient rather than the object or the disease Today the effectiveness of a medical treatment in terms of eradicating or limiting physiologic disease is no longer a priori considered sufficient in moral terms, as we will discuss in more depth in chapter eight The growth of quality-of-life research is indicative of this development (Musschenga 1987) As Widdershoven states, the result of the "crisis" in bioethics was that

> Hippocratic thought has lost its hegemony It must tolerate thought in terms of autonomy alongside itself and in many cases will have to recognize the supremacy of the autonomy principle (Widdershoven 2000, translation ccw)

The dominant mode of medical ethics soon emerged to be what is referred to as deontological "rule-based" or "principle-based" applied ethics (Widdershoven 2000, van Willigenburg 1993, Beauchamp 1989a) Deontological ethics mainly centers on the nature of the act itself it is believed that these characteristics in themselves can determine if a certain act is morally acceptable or not (van Willigenburg 1993) Four basic moral principles or "public moral norms" that are considered strongly universal, guide rule-based ethical analysis rather stringently beneficence, nonmaleficence, respect for autonomy and justice (Beauchamp 1989a, van Willigenburg 1993)

The fact that this perspective on ethics became popular in the 1970s is not so surprising In the early days of medical ethics, practitioners of this discipline were quite

often schooled in theology, a discipline whose roots are almost by definition deontological Secondly, as we have shown, deontological ethics was shaped strongly by the desire to safeguard patient autonomy against the powerful "consequence-based rhetoric of medicine" so to say The next example by van Willigenburg illustrates this point

> A physician can choose to apply chemotherapy because this will most likely strongly inhibit the growth of a melanoma and as such serves a good goal But what if the patient does not want that because he is tired of many heavy treatments Is it not a moral demand to listen to the patient's wish, even if it does not serve his self-interest? (van Willigenburg 1993 translation ccw)

Thirdly, it is likely that any professional discipline, such as medical ethics soon became, thrives better if it operates within a transparent "rational" frame This certainly seems likely if it wants to be accepted as a discipline by "hard" medical science (Arras 1997) Failing to do this could imply that "bioethics somehow becomes a grassroots political movement, neither welcome within, not seeking to be welcomed by, the hospital and the academic medical center" (Brody 1997) The post-modern preference for context and difference is perhaps better suited for an academic rather than a professional discipline dealing with concrete casuistry that demand solutions

Critique on rule-based ethics

While deontological rule-based ethics succeeded to establish itself in the academic arena of medical schools worldwide, eventually critique did arise Rule-based applied ethics represents a deontological or "master narrative" perspective on moral problems, implying the following disputed assumptions (Oderwald & Rolies, 1991, Hare 1989, Arras 1997)

1 Real life moral dilemma's conform to a pre-determined set of moral laws, implying that no essential information is lost in the translation of the dilemma as it presents itself to the ethical representation thereof

2 There is a "closed set" of moral laws which in themselves are beyond any question, whether or not the person experiencing the dilemma is actually (aware of) applying them or not

3 The implementation of the resultant conclusion in the field where the moral dilemma arose will do good, whether or not the people involved experience this as such

The most anticipated critique was that rule-based ethicists did in fact the same as physicians had done before like physicians, ethicists assumed to "know" what was "good" for patients, did not consult the people involved to evaluate utility of principles in

a specific context in spite of the secularization of society that weakened the basis under the assumption of universal values. Nonetheless these ethicists did not hesitate to "impose" their convictions on patient and physician alike. Similar to Derrida's critique on the "lab coat" approach of structuralist linguistics, critics felt that the rule-based method failed to elicit ethical dilemmas in their true color and depth (Derrida 1970; Nelson 1997).

> When the sick person is trying to find her own voice while being subjected to medical treatment, it is not at all clear that bioethics does any better than modern medicine in helping rather than hindering that process...The dominant principlist approach to bioethics says that the voice worth listening to is the one that expresses itself in terms of certain abstract ethical concepts. The patient's life experience has to be translated somehow into autonomy, beneficence, nonmalificence, and justice before we can draw any moral conclusions - and it is hard to imagine the average patient being able to carry out that translation unaided by us experts. (Brody 1997)

Oderwald and others have illustrated for example how the Enlightenment ideal of liberation and autonomy, that was central to the rise of deontological ethics, may have turned against itself: new social institutions may arise, institutions which aspire to make man free and autonomous yet end up dictating *how* one can be free (Oderwald 1991; Flax 1991). Or in words of Jane Flax:

> The escape from tutelage through reason and knowledge that Kant believed was also the path to freedom may, it seems now, lead instead into an ever more terrifying enslavement to the products of that knowledge. (Flax, 1991, 9)

While physicians have been convicted of seeking cover behind the assumption that a medical decision cannot be left up to the patient because he or she can't grasp the technological complexity involved and cannot overlook the situation at hand (Widdershoven 2000), some rule-based ethicists appear to reason along similar lines: patients are assumed unable to understand the moral complexity and existential depth of their acts let alone the moral range (implications beyond the individual) of these acts. Upgrading autonomy as the single determining value is no panacea either. Widdershoven defines the problem of a liberal autonomy-centered principle-based ethics as follows:

> Since respect for autonomy is conceptualized in terms of non-interference, there is no space to explore the question how the patient can be supported in shaping his own life. The principle approach sees autonomy as being guarded against influence from outside. This has been labeled negative freedom. There is no space for a concept of autonomy as a positive freedom, that is as active self-determination with the support of others. (Widdershoven 2000 - translation ccw)

Hence, the question is how one can proceed with bioethics given these complex questions. Several answers have been provided to this thorny issue. Widdershoven lists the phenomenological approach, the narrative approach, the hermeneutical approach, the

discourse approach and the care approach as some of the new directions in medical ethics (Widdershoven 2000). What all of these approaches have in common is that they constitute a "personal turn" to moral theory, that one can no longer suffice with a summary of the "facts of the case" and preset universals, but one will have to engage in dialogue to visualize the story people have to tell, the values they hold and the deliberations they make (Nelson 1997).

> Stories reveal the aim of acts, which values are aimed for in acts. They also show which problems people encounter in realizing the values they hold and how they attempt to deal with these problems. Stories reveal the values people hold highly and how they try to implement these values in practice. (Widdershoven 2000 - translation ccw)

From this wealthy body of material we can not only best come to understand why people do what they do, but also best judge if we can agree with what they do.

The alternative of "narrative" ethics

Narrative ethics is an important alternative to the outlined classic form of ethics, and gained influence in the 1980s (Nelson 1997). Narrative ethicists are very much interested in the shape and form of the medical dilemma in the context in which it arises. As Nelson states, narrative allows philosophers to work "up close - to put faces on faceless generalizations, to take the particulars of a given situation carefully into account" (Nelson 1997). This ethical school feels that, while it does not neglect the significance of moral laws per se, one *must* engage in the actual context in order to get a *sense* of the issues involved and the meaning attributed to them. While some narrative ethicists feel that the range of their discipline proceeds beyond this and leads deep into the complex issue of ethical justification, we prefer to stick to the less controversial definition of narrative ethics that perceives of narrative as a "supplement to an ethic of principle" (Arras 1997). The relation between narrative and ethical justification remains unclear as Arras states:

> In spite of the current enthusiasm for narrative and the plague of stories it has engendered, we have not gained much clarity about the precise meaning of narrative ethics and how it relates, or should relate, to ethics in general. [...] In particular, the connection between narrative and moral justification remains maddeningly obscure. What, one wants to ask, is the relationship between narrative and the achievement of moral justification, between the telling of a story and the establishment of a warrant for believing in the moral adequacy or excellence of a particular action, policy or character? (Arras 1997)

Though objections regarding this advancement of narrative are certainly possible - most importantly the uncertain relation between what people say and what they do in their lives (de Boer 1997) - we feel that the story people have to tell is precious if we want to

grasp the decisions they make and as such are of ethical relevance. Or as Widdershoven states:

> The narrative approach emphasizes that stories reveal something about how people deal with health and disease that is different from the rational view propagated by physicians and ethicists. [...] People only know who they are and what they must do if they have command over stories that structure their experiences and give their lives direction. (Widdershoven 2000 - translation ccw)

As Hare states, this is particularly true if two (or more) intuitive convictions conflict in a particular case, which is rather likely in our secularized world (Hare 1988; Widdershoven 2000). Dutch philosopher van Tongeren postulates that the physiognomy of specific experienced moral problems is rooted in more fundamental or general moral categories or categories of "meaning" (van Tongeren 1996). The next excerpt illustrates this argument eloquently:

> When the ethicist only offers formal expertise by clarifying the question, the premises and possible argumentation, or when he invests his knowledge in formulating solutions through a fixed sequence of principles or by attempting to reach consensus through equally fixed proceduralism, in other words when he chooses to abstract from the level at which the problem is rooted in the experience sphere of man, he transforms a concrete problem to an abstract problem. Rather the ethicist should attempt to show us what the problem means, what the fact that it strikes us and that it strikes us as a problem has to say to us, which meanings underlie the problem and constitute it. (van Tongeren 1996, 87 – translation ccw)

Inherent to narrative-driven ethics is that it is very much interested in *why* people do what they do, rather than being exclusively concerned with *what* people do, and it is felt that the stories people tell are essential in this respect. It is therefore perhaps an ethics of the inner world more so than of the outer world and as such inevitably related to bodies of knowledge that assist in understanding why people do what they do, such as psychology and anthropology. It may be argued that this turn of ethics is a natural one in our post-modern secularized era, where fewer moral laws or intuitions stand uncontested than ever before. Indeed as Merleau-Ponty has argued, the "kosmotheoros" perspective on morality is not of man but rather of the divine (Merleau-Ponty 1945; McGrath 1998). Surely some "laws" still stand, but mostly we seem to be dealing with "values" which require a much more profound analysis of context to reach a final judgment (Hare 1988). While values are not strictly individual (thus vexing nihilism) the degree to which they have meaning and their relationship to other values may differ from context to context. In his theory of reflective equilibrium Rawls states that he perceives of "principles" and "cases" being dialectically related (Rawls 1971). Both are felt to contribute to moral reasoning, the "principles" providing a normative frame while the "case" provides case-based judgments (Nelson 1997). Indeed we would like to underscore that our collective moral vocabulary can be arranged in more than a single way and that the specific order - which principle is "overriding" in a specific context (Hoedemaekers 1998; Hare 1988) -

is dependent on the specific context of the case narratives therefore provide "an indispensable and ubiquitous feature of the moral landscape" (Arras 1997) We agree with van Tongeren that one shall first have to listen carefully to others in order to create an understanding of the moral dimensions of a specific situation (van Tongeren 1996) While we do not assign to moral nihilism such as evident in the preference of some post-modern ethicists for the *petit recit* in which "narrative" and the authenticity of the narrator appear to play the role of substitutes for ethical justification, which ultimately must assume a private moral language, hence do not claim that morality is exclusively local (Arras 1997, Tronto, 1993), we would contest that narrative is a strong supplement to ethics (Arras 1997) It is felt that to get a deeper and more detailed understanding of the moral dimension of a case, one must involve narratives explicitly (van Tongeren 1996, Hoedemaekers 1998) Paraphrasing Arras

> Narrative provides us with a rich tapestry of facts, situations, and character on which our moral judgments operate Without this rich depiction of people, their situations, their motives, and so on the moral critic cannot adequately understand the moral issues she confronts (Arras 1997)

We do not perceive of narrative as the *alpha and omega* of moral reasoning however In this sense we take the critical notes of philosophers such as De Boer, Mink and Ricoeur at heart (Widdershoven 2000, De Boer 1997, Mink 1970, Ricoeur 1983) All three have underscored that the stories people tell about why they did what they did do not necessarily *coincide* with the actual context in which they acted, that the story people tell is at least a transformation of the event it narrates about (Widdershoven 2000) Indeed there are limits to the usefulness of narrative in ethical studies (Hardwig 1997)

> Without doubt, the patient's self-story will, under most circumstances, be the best account we are likely to get about that experience, at least at the start of the inquiry But all of us have, at one time or another, told a narrative about our experience that we would admit, upon reflection, was seriously defective or misleading (Brody 1997)

One of the main problems lies in the observation that the assumption of a single authentic or authoritative story is fallacious

> I am also very much interested in what the broader, outside audience thinks of me [ ] The first thing this causes me to do is to tell my story in light if the ideas I have about the beliefs and values of the audience I tell different stories for different audiences (Hardwig 1997)

This is even more likely to occur in the case of subjects with a high personal content or subjects that are likely to provoke controversy As such Hardwig concludes that we should view autobiographical texts differently

> The alternative is to acknowledge that an autobiography is only one account of a life, a deeply fallible and often unreliable account at that Moreover, all of us live in and tell many autobiographies Consequently, insofar as narrative bioethics requires an accurate account of a life or an illness, we need to piece together the narrative by attending to many stories told by many tellers (Hardwig 1997)

This leads Hardwig and Brody to the conclusion that bio-ethicists should not simply record autobiographies but should act as active biographers as well This implies that we should not avoid our role as critical interpreter in talking to parents and analyzing their narratives

Potential pitfalls of narrative ethics

If the effectiveness of a medical treatment is no longer sufficient to justify its implementation, what is, who is to determine this and by which standards?

> The moment that medicine ceases to limit her scope to traditional outcome parameters, such as lifespan, manipulation of the medical-biologically defined illness process and physical side-effects, everything becomes potentially relevant (Musschenga 1987 – translation ccw)

The expansion of the moral judgment of medical treatments beyond effectiveness potentially gives way to a new kind of "paternalism" which may be worse than its predecessor, fuelled by an authoritarian view on which preferences or life-styles are endorsed and which are not The focus on the subject of the patient opens the door to existential debates a broad and profound understanding of the existential roots of an individual patient is perceived as a prerequisite to reach a sound moral judgment in most post-modern ethics It appears however that the interpretation of the existential significance to moral debates has been raised well beyond the direct domain of the patient him or her self Most noteworthy in this context is perhaps the concept of medical consumption and the discourse surrounding it Clearly medical consumption or consumerism does not refer to the *direct* awareness of the patient, rather it is a meta-concept that nonetheless directs the moral debate significantly Central to this concept is the notion of medicine as an institute of hope or a repository of human suffering By doing so the discourse must assume "real" and "false" suffering and moreover must assume to possess the wisdom to make such a distinction

Indeed as Brody warns that post-moderns ethics can "dismiss" the patient's story just as much as Hippocratic ethics or rule-based ethics can

> If one is looking for a reason to dismiss a sick person's story, one can just as well do so because the story isn't post-modern enough (Brody 1997)

The risk of value judgments thus remains: for example, dismissing some stories because they are considered "a defective story of chronic illness" that "will ultimately set up the individual for greater suffering if not replaced later by a 'better' narrative" (Brody 1997). Two other examples of this are the debates surrounding cosmetic surgery and in-vitro fertilization. Patients seeking medical attention in either two domains are sometimes perceived of as *misinterpreting* their suffering. While this perception is certainly supported by some casuistry its broad application must rely on what we would call personal preference.

May's analysis of the legendary Dax Cowart case, a severe burn patient who explicitly requested his physicians to withhold further treatment, also shows this danger eloquently (Widdershoven 2000; May 1989). May positions himself above Dax Cowart's will not to live, really based on the conviction that Cowart did not fully *comprehend* the catastrophe he was suffering and therefore was unable to formulate solutions most fit to this catastrophe. Dworkin argues from a similar position as he feels that what is paramount is not so much the principle of non-interference but rather that "the choice [people make] is in accordance with the life plan of the person, that the person identifies with it" (Widdershoven 2000). This requires "reflection", something at which not all patients may succeed independently. However sound May's and Dworkin's arguments may be, the assumptions that facilitate them are rather similar to those of the days of Hippocratic ethics and hence yield the same risk of paternalism. Yet a priori allowing autonomy to prevail is not the solution either. May is likely correct when he assumes that patients do not always readily know what they are seeking. Brody is likely correct when he postulates that social-relational factors can influence how patients verbalize their demands (Brody 1992).

As ethics transgressed from its early themes of end-of-life decisions into new theme's with high "life-style" content, such as in vitro fertilization, cosmetic surgery and medical attitude, the danger of new "master narratives" and consequent paternalism has only grown larger (Arras 1997). This danger is illustrated by the case of the Quality of Life debate (Musschenga 1987). As Musschenga has illustrated, while the call for Quality of Life began in the 1950s and 1960s as a celebration of positive "subjective experience" so to say, it soon evolved into a new normative frame as may be depicted by the rise of standard questionnaires in medical trials. Initially Quality of Life research was intended as a "contrast concept" vis-à-vis medicine's one-sided and short-sighted "fixation of extending life". As a derivative of the socio-political movement that preceded it, and that claimed that "what counts is not the quantity of our goods but the quality of life", it called upon physicians to expand their horizon to the quality of the life that they aimed to extend (Galbraith 1967; Musschenga 1987). Yet while initially many of those who operated the concept refrained from clarifying the concept, which is in part explained by its function as a "contrast concept", the endeavor soon resulted in clinical-trial-ready definitions of which pre-set elements of life exactly constituted "quality", definitions that no longer require scrutiny into subjective experience really. That fixed

definitions of "quality" risk paternalism becomes clear from the argument of those opposed to the hegemony of societal quantity or prosperity as well: "when we assume prosperity as the highest goal, we neglect that the things that people wish for themselves need not be good for themselves and can be harmful to others" (Musschenga 1987). Brody suggests that we may prevent this pitfall by "constantly demand cross-checking and critical reinterpretation" (Brody 1997). The story told by the patient is central in this respect (Lauritzen 1996).

> Ultimately, for our ethical reasoning to be sound, we must check the coherence or the "fit" of carefully and truthfully narrated personal experiences against our ethical theories and their applications, and vice versa. (Brody 1997)

Consequences for this study

Setting out a course of describing how and why some parents choose for a cochlear implant while others do not is not a simple task. This is largely due to 1) the weight or impact of the choices being made, 2) the fact that the choices refer to someone other than oneself, 3) the fact that the other in question is related affectively to the person making the decision, 4) the uncertain outcome of the decision and 5) the highly active cultural context in which the choice is made. It is obviously a very different and much less monolithic inquiry than an inquiry in, let's say, the choice of a vacation destination. In general such a choice has relatively low weight while the relevant cultural context is less of a factor. People may choose to visit Indonesia because they enjoy adventure and fancy experiencing different cultures while others may prefer Cannes because they enjoy the sun and sea. Certainly cultural values may play a role. The university-schooled traveler for example may not want to identify with the Dionysian connotation that is attributed to a sun-seeking holiday. Notwithstanding potentially more profound and complex analysis of such choices, for most people it appears they are superfluous indeed: only few people will experience the profanity of the choice they make and ponder extensively about it. Parenting is a different story however, or perhaps has become a different story. The parenting of a deaf child is in some respect a *hyperbole* of parenting in general. While parents of a normal child may ponder over the choice of a school, he or she will know that the impact of such a choice will be marginal at best thereby softening the potentially tormenting sense of responsibility. This is not the case for parents of deaf children: the impact of these choices - and therefore the responsibility of parents - are *profound* and *final*. The moral judgment by influential others on the choices made is likewise a hyperbole of those encountered in general parenting. While some parents may for example disapprove of the "discipline" incorporated in the child rearing of other parents, such disapproval will rarely be profound. It may be the subject of a brief quarrel during the Sunday barbecue, but it will generally not bring a parent to seriously question him or her self and will rarely undermine friendships. In the context of deaf children this is not

the case Disapproval is commonly fierce and profound and strongly aimed at the parent as moral agent

The above implies that one cannot navigate on a simple question-answer scheme if one aspires to elucidate how the choice for or against a cochlear implant is made One will have to probe explicitly into the parents' story, attempt to exhibit the breath and depth of their experience To be able to do so, one will have to be aware of the shape and color of the cultural context in which these parents speak and make their decision This cultural context does not expose itself "naturally", one will have to engulf oneself in the literature on deaf education and actively seek dialogue with key figures in the Deaf community and deaf institutes to get a sense of it Indeed it appears that one of the main sources of misunderstanding about the experience of parents of a deaf child is situated in the lack of knowledge about the cultural context in which they move people who do not understand how a parent could choose not to implant his or her deaf child often do so because they lack knowledge about the cultural context of these parents For this reason we will attempt to provide information about this context throughout the text We will not only provide an account of what parents said, but also attempt to illustrate in which context they said what they did We will use a wide range of sources to draw this image, ranging from standard texts on parenting and deafness, to autobiographies, citations from Internet newsgroups and personal accounts Drawing the cultural context of parents of deaf children without reflection on the content of this context would be a missed opportunity for more than one reason Firstly, because the nature of what is being said sometimes is so preposterous and confusing that it demands a response Secondly, because deconstruction of some of the content of the cultural context visualizes its core Thirdly, because parents themselves also frantically attempt to reflect on this context in their quest for a responsible course The content of the cultural context in which parents of deaf children move is not transparent nor non-debatable Parents attempt to find their way through it, attempt to distinguish fact from fiction and try to extract values on which they can reflect to set their course We will follow parents in their quest, yet at times we will also provide an inquiry which parents themselves did not provide In a sense we will act as a parent ourselves, engaging ourselves in the debate, *experiencing* the debate, searching for facts, eliminating fiction, probing for values and referring these values opposite to dominant ethical theories This quest leads to general theories on parenting, on the relation between society and minorities and even political-philosophical views on society While it is not the primary purpose of this thesis to engage in elaborate discussions about the latter, we will provide some material for discussion where it is judged useful

POSITIONING THE METHODOLOGICAL PERSPECTIVE

Introduction

The methodology of this study follows closely from the ethical perspective that we outlined in the previous section If one decides for a narrative approach it follows logically that the empirical approach should be able to *unlock* this information the best way possible In this section we will argue that a "qualitative" methodology is most fit for such purposes

Qualitative versus quantitative methodology

The classical method of quantitative empirical science has been described by Popper (Popper 1992) Popper's "circular" method of deduction and induction still stands model for much of science today A central theme of good science is that different scientists can reproduce results in a fixed or standardized setting This demand has placed the social sciences before a considerable problem, since standardizing the social phenomena under scrutiny is rather problematic To conform to the demands of empirical science nonetheless, there has been a retreat to the use of standardized questionnaires Yet this choice has been criticized much similar to the critique on rule-based ethics and quality of life research that we discussed in the previous section The most prominent critique is that the questionnaire methodology *reduces* the reality under scrutiny to the framework of the questionnaire

Dilthey was highly skeptical of the suitability of such methods in the social sciences (Dilthey 1977) He felt that there was a clear distinction between the "Naturwissenschaften" and the "Geisteswissenschaften", a distinction that ought to be expressed in the methodology of choice (Dilthey 1977) Nonetheless, the social sciences took a strong turn towards quantitative methods in the twentieth century It was not until the 1960s that the method debate surged once again The inability of quantitative methods to elicit social phenomena was once again stressed social phenomena were to be perceived as "socially located evaluations" rather than measurable "objects" Though social phenomena can be analyzed quantitatively, this process may cause important information to be lost Harre has described this convincingly in the context of psychology

> It may be that in some cases generality can only be achieved by reaching for higher and higher levels of abstraction For example in studying human emotions we find that there are great differences between the repertoires displayed by people from different cultures By talking of "affect", a term invented by psychologists for all forms of bodily feeling at a

> very high level of abstraction, a kind of generality is achieved, but almost all the psychologically relevant features of our emotional lives are lost (Harre 1997)

Though the dichotomy between quantitative and qualitative methodology is arbitrary to some extent, Hammersley names several issues that do separate quantitative from qualitative research (Hammersley 1992) One of the most central differences is that qualitative methodology operates an inductive approach rather than a deductive one, which makes it suitable to "identify cultural patterns" rather than "seeking scientific laws" (Hayes 1997) Critique on quantitative methods in the social sciences emphasizes that questionnaires do not solve the methodological dilemma of social sciences but rather enlarge them through concealment As we discussed vis-à-vis the Quality of Life debate, designing a questionnaire requires that questions and possible answers are formulated a priori It will thus require a *plan de campagne*, containing explicit notions of what one wants to know and how one can go about elucidating them Needless to say this is a potential source of bias In addition it is stressed that social phenomena are unfit for the patterned approach of quantitative science Social phenomena are erratic and narratologically ordered which renders them unfit for study through questionnaires Additional bias problems arise in the interpretation phase The Duhem-Quine thesis states that there are *always* competing interpretations and that the selection of one involves a subjective evaluation process One always interprets through a specific registration system (Huttner 1995) This system involves both theoretical as well as social-cultural-psychological elements psychologists, linguists and philosophers are likely to view a specific discursive truth differently Gadamer speaks of "anticipating expectations" in this context (Gadamer 1972)

The above-mentioned critique has been a strong incentive for the advancement of qualitative methodology in the social sciences (Silverman 1993) It is crucial however to state that the field of qualitative research is not a homogeneous one rather it encompasses a wide range of views, ranging from semi-quantitative to n=1 experiments Today qualitative studies are well established, not only in the social sciences but in medical science as well (Sackett 1997, Hayes 1997) In a 1997 editorial in The British Medical Journal Sackett and Wennberg argue that much of the squabble over methodology is rather senseless in itself and we would do better asking ourselves which research question demands which methodology

> Our thesis is short the question being asked determines the appropriate research architecture, strategy, and tactics to be used - not tradition, authority, experts, paradigms, or schools of thought If the question is 'what is the importance of patient preference in the choice of treatment for benign prostatic hyperplasia?' the appropriate study architecture, strategy, and tactics are those that identify and characterize the reactions of individual patients to their disease and their assessments of the risks and benefits of alternative treatments through open ended, in depth interviews The fact that this array of approaches is called qualitative research is irrelevant to whether this is the best way to answer this question If the question is, 'In men with benign prostatic hyperplasia is laser prostatectomy

> superior to transurethral resection of the prostate in terms of symptom relief, blood loss, and length of catheterization and hospital stay?' the appropriate study architecture, strategy, and tactics are those that assemble a group of individuals with this condition, randomize them to the alternative procedures, and achieve complete follow-up of their subsequent outcomes. The fact that this combination of approaches is called a randomized clinical trial or efficacy research is irrelevant. (Sackett 1997)

In recent years qualitative research has been criticized as well. The critique is once again rather similar to the pitfalls of narrative ethics discussed in the previous section. Releasing the disciplining requirements of quantitative science potentially opens the door for subjectivity and suggestion (Knutson 1997b). In particular the more radical methods, focusing on "personal account" rather exclusively, have been the subject of criticism. One particular element of the critique is the assumption by some qualitative scientists that a single monolithic truth exists. Juxtaposed to this view is the opinion that people hold a range of truths and that the specific truth elicited will be contextually determined. Subjects are active agents in an interview setting and respond to the status of the interviewer, the tone and shape of the questions asked. Freeman for example has claimed that neglect of this active role of study subjects led American anthropologist Margaret Mead to her views on Samoan youth (Freeman 1997). Much like what we said about narrative ethics, this implies an active role of the researcher. Yet if the researcher plays such an active role, how can we prevent subjective interpretations? Indeed as Hüttner states:

> It is a great advantage that one can say something about issues which cannot be observed directly, but where does it stop? The danger exists that the procedure will be utilized only to speculate about issues which cannot be studied empirically in any way. (Hüttner 1995)

To counter this critique it is argued that not every interpretation is *equal* in value: while a narrative or text may have an open character, this is not limitless. A narrative or text "speaks" for a reason, with a certain goal, under specific circumstances and with the intent of a certain effect. Robinson proposed that personal narratives can be told to entertain, to argue or persuade, or to resolve uncertainty. Each function is associated with a mode of conversation that imposes constraints on the content and organization of a narrative and ascribes roles and privileges to teller and listener. Through these interactions meaning is shaped. (Robinson 1996). This implies an active attitude by the researcher to check his or her interpretations for "fit". If an interpretation does not match with the narrative a bona fide scientist will have to modify his or her interpretation (de Boer 1988). Interpreting is therefore an open interaction between narrative and the interpreter. It is therefore of the utmost importance that a scientist stands open for a dialogue with the text. Interpretations should be matched to the text continuously (Glaser 1967). While an interpretation does not need to be literally congruent with the text, the text should be able to recognize itself in an interpretation. If not, the risk arises of a "violent interpretation" is all too real.

Consequences for this study

Congruent with the social nature of the phenomena under study in this thesis and in line with the ethical approach of preference, this study is based on qualitative semi-structured interviews. This implies a compromise in methodology, representing a "hybrid" approach if you will. In doing so the following issues are assumed. It is assumed on the one hand that the parental experience is unique to some degree, which explains the need to allow parents to narrate freely about their experience. Interviewing parents of implanted children is a delicate matter. These parents have been confronted with an intensely emotional experience and move within a highly polarized environment. In many instances, these parents never previously had the opportunity to speak freely about their experiences (Gregory 1995). These conditions demand prudence and underscore the importance of creating a "trusting relationship" (Booth 1994). Enforcing specific items onto parents in a structured format can be quite damaging from this perspective. It is also assumed however that the issues involved have a *specific* context and history which is likely meaningful to parents. This context and history exposes itself in the tradition of deaf research as well as personal accounts by key figures in the field. There is a considerable body of literature regarding deaf education in general, the role of parents in the decision-making process and cochlear implantation in particular (Gregory 1995; Blume in press). In addition, key figures such as Deaf adults, deaf educators, deaf institute staff and social workers can provide valuable insights into the issue at hand. Therefore, a detailed study of these sources was performed, extracting a provisional item list (see appendix). In the actual interview setting the item list was present in the mind of the interviewer so to say. It was not enforced onto parents but rather employed as a translucent guide leading to specific probes when appropriate. Finally it is recognized that an exclusively subject-based approach to human experience is both a source of valuable insight as well as well as a potential source of clouding, therefore demanding a more explicit role of the investigator (Duck 1991).

WORK-UP & METHODOLOGY

Introduction

Having outlined our ethical and methodological premises in the previous two sections we will continue with a to-the-point description of our methodology in this section We will describe what sources we consulted in preparing the empirical phase and how this led to a global item-list for the interviews with parents Next we will discuss how we determined inclusion and exclusion criteria and describe how respondents were selected and recruited based on these criteria We will describe the interview procedure as well as the transcription and analysis process in detail

Literature-search and key-issues

On initiation of this study knowledge of cochlear implantation and the controversy surrounding its implementation in pre-lingually deaf children was very limited The first months of the study phase were therefore reserved for an intensive literature study This was meant both as a general orientation on the issue as well as a means to identify "foreshadowed problems" that we needed to translate in an interview protocol (Malinowski 1922) Journal literature was gathered through the Medline and Psychlit databases Relevant books were located through the electronic library databases of Adamnet, the Catholic University Nijmegen, Harvard University (Hollis catalogue) and the Royal Dutch Library The personal news archives compiled by the IvD at Sint Michielsgestel was also consulted to get an idea about how cochlear implants were presented in the popular media Additionally Internet resources were consulted In particular the "personal accounts" that are available through newsgroups such as Deaf-L, UK People Deaf, Beyond-Hearing and Cochlear Implant Forum were helpful For a comprehensive literature list we refer to the bibliography

Besides printed and Internet resources we also arranged meetings with "leaders" in the field of deafness Many of these contacts eventuated into an animated exchange of ideas that contributed significantly to our empirical protocol An explicit attempt was made to involve the Deaf community early on As such we did not only consult with Deaf leaders but also sent out a mailing through the database of the Dutch Federation for the Deaf (Dovenschap) Forty representatives of regional Deaf organizations were requested to provide input regarding interview topics However, with only two reactions the response was disappointing

Based on the above-mentioned information we extracted a global item-list containing subjects that we wanted to discuss with our respondents For a comprehensive checklist we refer to the appendix.

- Information on the interview procedure
- Background information regarding deaf child
- Experiences leading up to the diagnosis
- Experiences around and shortly after the diagnosis
- Experiences with deaf schools and Deaf culture
- Parenting values and goals
- The cochlear implant decision
- Experiences regarding the implant procedure and revalidation period
- Post-implant judgment and evaluation

Planning the selection process: time and inter-subjective variability

If one sets out to describe the decision for or against cochlear implantation based on personal interviews one must assume some degree of inter-subjectivity or generalizability. While each story is ultimately personal, the experiences encountered as well as the language in which these experiences are worked-through and narrated are likely to have much in common as well. A story that strands in its personal idiosyncrasy is incomprehensible for the interlocutor, which renders it useless for the purpose of this study (Wever 1997).

One of the main tasks of the interlocutor is to distillate a narrative that may not be identical to any individual story yet with which most or all narrators can identify To achieve this, one must be aware of the characteristics of the narrators that are likely to allow this without excluding relevant "alternative voices" The inclusion of all possible alternative voices however may imply a compromise on the clarity of the main story In a recent study on the experiences of people with a disability this is illustrated by frequent excursions to the specific character of each individual disease experience. while the experience of people suffering from multiple sclerosis may have a lot in common with those missing a limb there are distinct differences as well (Wever 1997) While in principle all parents are suitable candidates there are some conditions that are likely to influence the experience in such a way that they fall beyond the target of this study We will discuss some of these conditions and will discuss if they should or should not influence the selection process.

Time is an important concern in the study of experiential issues in general This is particularly true in the context of medical events Many medical events have a protracted course, yielding different within-subject sub-events along the time-axis, thereby manifesting different experiences and requiring different responses Many studies have illuminated this phase-like course of the experience of people with a chronic illness

(Wever 1997) The "tasks" with which an ill person is challenged are different in the pre-diagnostic period compared to the period directly following the diagnosis Similar differences may arise after many years of illness experience Deafness also typically follows a protracted course, presenting parents with distinct circumstances As an example of this, many years typically elapse between the moment of deafness and the time of cochlear implantation The events around the time of diagnosis may represent a distinct experience to some degree The same may be true for the concrete deliberations regarding cochlear implantation Parents who are interviewed directly post-diagnosis may be preoccupied with different issues than those who have found a new equilibrium in terms of school, communication and emotional adaptation Similarly, parents interviewed shortly after implantation are perhaps more likely to respond in somewhat different terms than those who have experienced the victory or failure of the procedure some years later The above implies that selection of cases is not an uncomplicated matter Selection of parents whose child was implanted only a short time ago has the benefit of disclosing their experiences in "real-time" so to say Yet, these parents are unable to recount on the final effect of implantation The significance of time-factors is not perceived in terms of selection or exclusion of cases Rather it appears more appropriate to acknowledge that time is a factor in *analyzing* the data and account for this role in the interpretative phase In concrete, it will yield an organization in the text that accounts for time, discerning early and late experiences

Another factor that may lead to differences in experience has to do with the specific (contingent) course of illness, its between-subject variability A woman cured of breast cancer after mastectomy may respond differently than a peer awaiting experimental chemotherapy due to relapse of the disease Likewise a woman with a small breast tumor may judge mastectomy differently than a peer with a large tumor In this sense it should be considered wise to account for the concrete context rather than chronology alone, even though the two may be related In terms of this study it should be noted that there is a relatively wide range of variance in terms of how a deaf child develops in terms of spoken language While some children for example make an astounding progress in the development of spoken language, others make very little headway indeed Furthermore the development post-implantation itself is also strongly protracted, extending over many years (Summerfield 1995) It is likely that what parents have to say is in part dependent on how far they have come with their individual child This study sets out to create an understanding of the context in which parents decide for or against a cochlear implant It is thus assumed that such a context exists, in other words it is assumed that some degree of generalizability of the results beyond casuistry is feasible It is hypothesized that the prospect of speech and spoken language is an important ingredient of the context that we aspire to describe Unpredictable variance in prospects of speech development must be considered rather intrinsic to the cochlear implantation process and as such should not be considered as an in- or exclusion criterion a posteriori Yet, in selected cases this may not be valid that is if it is a priori known that a specific child has either negligible or outstanding opportunities for spoken language development Two extremes are

noteworthy in this context. On the one hand there may be children whose prospects of acquiring spoken language skills are so splendid that it renders the language controversy obsolete or at least makes it less of an issue. Though these narratives are interesting, we chose to focus on those parents who lacked the certainty of language development. On the other hand there may be children whose outlook of acquiring spoken language are insignificant, therefore also changing the character of the context. Indeed it may be argued that both theoretical examples have empirical correlates, though it should be emphasized that they represent a minority of pediatric implant candidates.

In order to identify these two potential groups, one needs to be informed about the factors that facilitate spoken language acquisition for deaf children in general and implanted deaf children specifically. In the past attempts have been made to predict which deaf children are likely to succeed in achieving spoken language. While none of these attempts resulted in a watertight model, there is some consensus on which factors are of influence on success (Northern 1984; Geers 1987). In their Deafness Management Quotient (DMQ), Northern et al. for example, assigned 30/100 points to residual hearing, 30/100 to the intactness of central nervous structures, 20/100 to intelligence, 10/100 to family constellation and 10/100 to socio-economic factors (Northern 1984). Regarding the first factor, others have contested that it would be better to navigate on the child's use of amplification rather than pure-tone averages alone (Erber 1974). The simple employment of IQ tests in selecting deaf children has also been criticized (Geers 1987). Geers et al. refined the DMQ into their Spoken Language Predictor Index (SLP): the SLP assigned 30/100 points to hearing capacity, 25/100 to language competency, 20/100 to non-verbal intelligence, 15/100 to family support and 10/100 to speech communication attitude. It is pointed out that both in the DMQ as well as the SLP, factors of influence on a child's ability to learn spoken language are largely innate rather than environmental. In terms of cochlear implantation an additional factor of major significance must be mentioned: age at which one becomes deaf. Gantz has shown that children deafened after they had acquired spoken language outperform pre-lingually deaf children (Gantz 1994). Another factor that appears to impact implant effect significantly is educational placement. Implanted children enrolled in a manual program have consistently performed relatively poor (Moog 1991; Tyler 1990) while quite a few of them appear not to use the implant at school at all (Rose 1994). Nonetheless many deaf children attending schools with manual programs have been implanted. This is also true for The Netherlands. Even though an increasing number of people are questioning this practice, implantation of children in manual programs is still very much routine. As such it does not validate exclusion in this study, however one should keep this factor in mind in analyzing the data.

Based on these arguments it appears that at least three categories should be excluded from this study: 1) those deafened after the age of language acquisition, 2) those implanted many years after onset of deafness and 3) children with the Usher syndrome. Children with Usher syndrome suffer from progressive vision loss in addition

to light to profound deafness Implantation of these children is aimed to allow them some sensory contact with the world rather than aiming to facilitate speech or spoken language Regarding the second category we add that it has been shown that pre-lingually deaf children implanted in early adolescence have a far lower chance of developing usable spoken language (Snik 1997b, Parisier 1993, Osberger 1993a) Today deaf children older than 8-10 years are usually excluded from implantation A fourth factor that should be considered here is the case of partial-insertion Van den Borne reports that a partial electrode insertion has a significant negative impact on implantation outcome (van den Borne 1999) Nonetheless this issue is non-conclusive in literature (Osberger 1994) Moreover, it appears that partial insertion is a liability inherent to the implantation procedure As such partial insertion was not considered as an exclusion criterion

A third time-related issue that has come to the forefront recently is that progress of time may alter how people reflect on events, including medical events (Conway 1996, Neissner 1976) While in the former two issues time is a correlate of *specific* events and may be expressed in terms of a event-task-response theory, the issue of recall-bias as presented by Adang et al is lesser so (Adang 1997) The change may be located in time as an expression of general change in personal circumstances It appears for example that people with even the most severe of chronic illnesses find new ways to appreciate life altogether (Wever 1997) Robinson states for example that as time progresses, people may attribute different meanings to specific events

> New information or an altered perspective can prompt us to reinterpret specific experiences or entire segments of our personal history Jobs we hated or people we regarded as authoritarian may, in hindsight, be seen differently The work was hard, but good experience the teacher was demanding, but prepared you for the competitiveness of the workplace (Robinson 1996)

The change may however also be expressed in terms of narrative reconstruction or perhaps denial Someone who is unable to find a job and lacks perspective for change may not benefit from negative meaning connoted to this situation since such could arguably lead to a depressed affective state Once a job has been conquered, such negative meaning can be experienced and expressed in hindsight without such affective injury Yet to conclude from this that the former experience was not "authentic" is not uncomplicated indeed as Robinson claims, "accuracy" may be the wrong category in this context, "both prior and current meaning can be accurate each has been constructed within a perspective that reflects the person's preferred ways of organizing experience" (Robinson 1996) In a longitudinal study of end-stage renal patients Adang found a divergence between self-reported quality of life ratings before renal transplantation and retrospective ratings after transplantation after renal transplantation people tended to rate their quality of life prior to transplantation considerably lower than they did in "real-time" (Adang 1997) Seemingly, if one has end-stage renal disease and no direct outlook for transplantation and such circumstances last many years, one finds ways to live and enjoy life Similarly, if one receives a kidney one finds ways to make that new

circumstance positive by contrasting it with the period before transplantation While one may argue that the first response is typical of denial while the latter is not, this needs not cover the range of the phenomena It thus appears, as has been shown by memory scientists, that people have the capacity to flexibly (re-) construct their life narratives conformable to concrete circumstances in such a way that specific irreversible negative circumstances are toned down This has led some authors to speak about "perspective" or "standpoint" instead (Robinson 1996) By Adang's thesis parents may have constructed their narratives in such a mode to allow both success and failure of the implant procedure, thereby potentially clouding their motives for choosing for an implant They may for example state that they chose for an implant primarily in the hope to provide "environmental awareness" to their deaf child, something their child may have acquired at that time and thereby effectively legitimizing their choice Selection of parents who's child was implanted several years back seems a much better strategy in this context The drawback is that one will have to strongly draw on recollection vis-a-vis the early experiences Additionally, conformable to Adang's thesis these parents too may construct their narratives so to validate their current circumstance It therefore seems logical to include both groups in this study, though with a mild preference for the more "experienced" parents, defined as parents of children who have their implants for at least 4 years

Selection process

The parents of the first 20 consecutively implanted children (AZN-IvD) were considered for inclusion Ten parents were excluded from participation 5 children were implanted after the age of ten, 3 children had Usher syndrome and one child was post-lingual deaf An additional child was excluded because of severe psychosocial problems, unrelated to the implant process The remaining 10 parents were invited to participate in the study through writing One parent dyad refused to participate without providing information on their motives Their female child was 11 years and 8 months (by 08/98), became deaf by meningitis at an age of about two years and was implanted at about 6 years of age The implant procedure was a technical success (full electrode insertion) The child attended a signing school for the deaf It was decided to replace this non-responder with the parents of the 21st and 23rd implanted child (the 22nd implanted child was post-lingually deaf) Both parent dyads consented

The profile of the 11 children is as follows 7 girls and 4 boys with an average age (by 08/98) of 11 years and 9 months (range 10 years 1 month - 14 years 2 months) Meningitis was by far the most common cause of deafness Almost three quarters of the children were implanted at least 4 years before the interview date, one quarter between 2 and 4 years (mean of 5 years 2 months) Average age at implantation was 6 years and 5 months At the time of the interview 5 children attended a signing school for the deaf, an equal number was mainstreamed while one child attended fingerspelling-based

education Based on the characteristics of the children who were implanted by the AZN-IvD team at the time it appeared that our sample was rather biased towards children deafened by meningitis Additionally there was a bias towards children attending mainstream education as well as children attending a predominantly signing institution The length of cochlear implant usage explains the educational bias as time progresses an increasing number of implanted children will transfer from deaf institutes to mainstream educational settings The etiological bias is explained by the fact that some reluctance to implant congenitally deafened children was manifest in the early days of cochlear implantation, a finding which also emerges from Graham's and Holden-Pitt's reviews of implanted children in the US (Graham 1995 Holden-Pitt 1997)

To correct this bias as well as to promote the story of parents with younger children who were implanted more recently, we decided to add parents selected from the most recently implanted (< 2 years) children with congenital hearing loss At the time of selection 18 parents fitted the first description Of these candidates 2 were discarded because of meningitis Four parents were excluded because of post-lingual deafness One child had a progressive form of deafness and was implanted at 3 years and 10 months Since this could entail post-lingual deafness, these parents were excluded Another parent dyad was excluded as their child was implanted after the age of 10 Finally one parent dyad was excluded because of a language barrier that would complicate the interview The remaining 9 parents were all invited to participate in this study Four parents refused to participate without providing information on their motives The children in question, all female, were on average 8 years and 11 months old and were implanted at an average age of 6 years and 11 months Three of four children attended a signing school for the deaf

In order to provide depth and contrast to the study it was decided to recruit parents of comparable (pre-lingual profound deafness, age, non-Usher) deaf children who did not receive a cochlear implant The primary recruitment method was an advertisement in a leading Dutch Deaf journal (Woord & Gebaar) A total of 7 parents responded As one would expect based on the epidemiology of deafness, none of the respondents were deaf themselves nor did they come from families with one or more deaf members While some respondents indicated that they had known one or two deaf individuals, these acquaintances were never personal but rather distant In addition, due to the reported age of these acquaintances and the fact that sign was not always the expressed mode of communication, it was unclear if these individuals were genuinely deaf or rather hard of hearing or perhaps suffered from presbycusis

16 cases and 7 controls finally participated in this study Respondents were the parents of a total of 25 deaf children, since two control parents had more than one deaf child A third respondent also had a second deaf child (C8), yet this child was still very young at the time of the interview and no additional information was provided on the child during the interview 56% of the children were female (n = 14), 44% male (n = 11)

Most children became deaf due to meningitis. Meningitis was a more common cause of deafness in cases compared to controls, which was also expressed by the age of onset of deafness: as much as 44% of cases became deaf after the age of two while 86% of controls became deaf in the first year of life. Additional disabilities were only reported by four cases. One child was reported to be dyspractic, one suffered from severe cardiac disease, one had a learning disability and a fourth child also suffered from thyroid disease, possibly in the context of Pendred syndrome. None of our controls reported additional disabilities. In most instances the deaf child was the first or second born child. Children of control parents were less likely to be first born. For specific case-sensitive characteristics we refer to table 2 and to the appendix.

Table 2 Respondent characteristics

	Cases	Controls	Total
Respondents	16	7	23
Deaf pedigree	1	0	1
> 1 deaf child	1	2	3
Divorced	2	0	2
Average age (y/m)¶	9/3	10/7	9/8
Children ≤ 6 years	4	1	5
Number of siblings	1 68	1 14	1 52
Rank¶			
• only child	• 0	• 1	• 1
• first born	• 9	• 2	• 11
• second born	• 4	• 5	• 9
• third born	• 2	• 1	• 3
• fourth born	• 1	• 0	• 1
Cause of deafness			
• meningitis	• 10	• 3	• 13
• congenital	• 6	• 4	• 10
Age of onset			
• birth	• 6	• 4	• 10
• 0-1 year	• 3	• 2	• 5
• 1-2 year	• 0	• 1	• 1
• 2-3 year	• 7	• 0	• 7
Additional handicaps†			
• dyspraxia	• 1	• 0	• 1
• learning disability	• 1	• 0	• 1
• cardiac	• 1	• 0	• 1
• syndrome	• 1	• 0	• 1
SES‡			
• I	• 8	• 2	• 10
• II	• 6	• 3	• 9
• III	• 2	• 2	• 4
Region§			
• North	• 5	• 2	• 7
• Southeast	• 8	• 3	• 11
• West	• 3	• 2	• 5

† as reported by parents

‡ highest schooled parent (I = high school and/or vocational training (mbo), II = college (hbo), III university)

§ At diagnosis North – Groningen, Friesland, Drenthe, Overijsel, Southeast Gelderland, Brabant, Limburg, West = Noord-Holland At the time of the interview 6 cases were in the

northern region (added with C11), 4 in the west (added with C13) and 6 in the southeast. Of controls 2 were in the northern region, 1 west and 4 southeast (added CO3).
¶ based on 9 control children: two controls had 2 deaf children, thus making the total number of control children 9 instead of 7, the total number of respondents 25 instead of 23.

Parents' characteristics revealed a rather high educational profile, with 57% of parents having obtained at least a college degree. Though parents of implanted children were somewhat lower educated compared to controls, still 50% had at least enjoyed college training. Indeed a Gallaudet survey has found that US implant families tend to be relatively wealthy and more likely to be highly educated, though this may be explained by the organization of health-care insurance in that country (Johnson 2000). Our control selection procedure is known to select for higher SES. At the moment of diagnosis, almost half of respondents (47.8%) lived in the southeastern provinces of the Netherlands. It appears that most parents were rather involved in the rearing of their child: 50% of cases and 57% of controls were active at the local deaf school level or in regional or national deaf advocacy. One parent couple was divorced at the time of interview, a second couple was divorced by the time of print: both were parents of an implanted child.

Table 3. School & Language characteristics

	Cases	Controls	Total
Initial school choice¶			
• Amman	• 4	• 2	• 6
• Guyot	• 6	• 2	• 8
• HoH‡	• 3	• 3	• 6
• IvD Oral	• 2	• 2	• 4
• IvD Fingerspelling	• 1	• 0	• 1
School at interview¶			
• Amman	• 2	• 1	• 3
• Guyot	• 4	• 2	• 6
• HoH‡	• 3	• 2	• 5
• IvD Oral	• 1	• 1	• 2
• IvD VSO	• 1	• 0	• 1
• Mainstream	• 5	• 3	• 8
Language at interview†			
• Speech	• 3	• 2	• 5
• Sign or TC	• 8	• 4	• 12
• Combination	• 4	• 1	• 5
• Fingerspelling	• 1	• 0	• 1

† At home

¶ based on 9 control children: two controls had 2 deaf children, thus making the total number of control children 9 instead of 7, the total number of respondents 25 instead of 23.

Sign language was by far the most popular home language with over half of our respondents reporting to communicate through sign most of the time (table 3). Initial school enrollment was largely in compliance to geography. All but 3 parents (CO1, C11 and C13) enrolled their child in the nearest school. Those who did not, all enrolled their child in an out of region *signing* school for the deaf. Of the three parents who relocated, one repatriated from a third world country (CO1). Three parents had considered an out of region school (C7, C10, C12): all considered IvD but eventually enrolled their child at the regional Guyot institute. It appears that parents conceive of schools for the hard of hearing as a serious alternative to "classic" deaf schools since one quarter of our respondents chose such a school. Controls were more likely to choose for a school for the hard of hearing; 3 controls initially enrolled their child at such a school even though a nearby deaf school was available. At the moment of the interview, the enrollment pattern had changed considerably. The most remarkable change was in mainstreaming: 5 cases and 3 controls attended a mainstream school. The number of mainstreamed cases is in concordance with the total AZN-IvD population: two years after implantation 28% attends regular school full-time (unpublished data from IvD). The relative older control population may in part confound the higher attendance of mainstream education by controls. In addition, two controls reported that their children had "some hearing remains", which may also have facilitated mainstreaming.

Two subgroups were identified based on the assumption that it may be fruitful to be able to recognize them throughout the text. Firstly "subgroup-A", consisting of all children who became deaf after the age of two and before the age of three. Language development had initiated in all these cases before the child became deaf. This subgroup will be identified throughout the thesis by the addition of the suffix "a" to their identifier (i.e. C9a). A total of 7 cases fitted this profile. On average, the children were also older than other cases at the time of the interview (11.2 years). Furthermore they represent the mainstreamed case population entirely. "Subgroup-B" consists of 11 parents who did not participate in school activities or deaf advocacy. 8 cases and 3 controls fitted this description. The subgroup was somewhat lower educated, with 4 parents having obtained at least a college degree. This group will be identified by the suffix "b" (i.e. CO8b).

In 1997 the birth rate in the Netherlands was 192.443 (CBS data). Davis reports that the annual incidence of hearing loss in excess of 100 dB is 24 per 100.000 live births (Davis 1997). Based on these figures one would expect about 46 new cases of hearing loss over 100 dB in the Netherlands per year. Eldik reports 85 deaf or severely hard of hearing children per birth cohort in the Netherlands (Eldik 1998). 61% are estimated to have hearing losses in excess of 90 dB, which would equate 52 children per year cohort. The suitability of cochlear implantation in children with multiple handicaps is debated,

particularly if severe cognitive deficits are involved Davis reports that about 26% of all children with hearing disabilities over 40 dB manifested multiple handicaps (Davis 1997) About 13-14% exhibit (profound) cognitive deficits (Davis 1997, Eldik 1998) A Gallaudet survey estimates that up to 40% of hearing-impaired children have significant additional handicaps, most commonly learning disabilities (12 8%) or mental retardation (11 3%) (Gallaudet 2000, Graham 1995) Taking into consideration the questionable suitability of cochlear implants in children with multiple or cognitive disabilities, it seems logical to reduce our estimate by 13-40% which would result in 28-45 new cases per annum suitable for cochlear implantation Based on these accounts, our total sample (n = 23) is estimated to represent 5-8% of all parents of profoundly deaf children suitable for cochlear implantation in the age group 4-14 years (Hoogeveen 1998, Davis 1997)

Neutrality of research group

As we outlined in the introduction of this thesis, the empirical phase of this study entails interviews with parents of deaf children Though the AZN-IvD implant team was a participant in the study, it was decided by all participants to execute the study independent of this center The coordination of the study was completely delegated to the Department of Philosophy and Medical Ethics at the Free University Amsterdam under the guidance of Dr A K Oderwald It was felt that this design was not only necessary in terms of expertise but also a fundamental prerequisite to safeguard privacy and to create a trusting environment so to stimulate parents to speak out freely about their experiences

Description of data collection

To safeguard privacy, selected cases were invited in writing to participate by the AZN-IvD implant team A letter by the Free University research team, describing the study design, was included in this mailing Controls were recruited through an advertisement in Woord & Gebaar, a Dutch journal for the Deaf read widely by parents of deaf children Parents were informed that participation was voluntarily The privacy procedure was described Parents were advised that the independent Free University research team coordinated the entire research process Parents were also advised that the audiocassettes of the interviews and typed transcripts would be filed by the Free University research team and would be treated with the utmost of privacy Consent was obtained in writing and those that consented were requested to contact the research team or provide information so they could be contacted Parents were allowed to decide on the date and location of the interview All respondents chose to proceed with the interview in their private home (Hayes 1997) All interviews were scheduled in the second half of 1997 and the first quarter of 1998 The actual interview was introduced by a verbal and off-record recapitulation of the study goals, the interview process and privacy safeguards At

this point parents were allowed ample time to ask questions All interviews were recorded on 90-minute analogue audiocassette material

During the interview a predetermined interview schedule was used as a general guide This is to say that though we aimed to cover all topics and also attempted to uphold the chronology of the schedule, the questions were explicitly open and we aimed to create a "conversational style" in which pre-set questions functioned as "cues" rather than "constraints" (Smith 1997, Pidgeon 1997) The interviews may hence be characterized as in-depth and explorative yet semi-structured at the same time Interviews lasted between 90 and 150 minutes Full-length typed word-processor transcripts were obtained of this audio material by semi-professional typists All typists signed a confidentiality waver Typists were asked to supply transcripts on floppy disk All other copies of the material were to be deleted The floppy disk material was copied on a single password-protected Personal Computer at the Free University department of Philosophy and Medical Ethics Printed hard copies and the original floppy disk medium were used as back up and were securely stored The compiled length of the interview material added up to 911 pages in single space Times New Roman 12 characters per inch

Description of the analytic phase

Analysis of the material was rather eclectic since we used a range of qualitative methods rather than upholding one single model In particular the relationship between theory and empirical material was neither purely "theory-driven" as in quantitative studies nor completely "bottom up" as in the classic grounded theory advocated by Glaser and Strauss (Glaser 1967) Still we feel that the emphasis was bottom-up the in-depth theoretical background of specific experiences with which many of the chapters initiate were mostly formulated a posteriori The process can best be described as a circular, iterative or "flip-flop" (Pidgeon 1997) qualitative process in which empirics and theory interacted continuously during the actual interview process, when labeling and compiling specific excerpts and during the writing process Contrary to quantitative methodology, this approach implies that data collection and analysis are not strictly separate activities (Pidgeon 1997)

After completion of the interviews, the total body of printed interview material was read scrupulously ("close reading") Important passages were highlighted in the text (Pidgeon 1997) As we went along we encountered recurrence of specific topics casu quo "patterns" in the material (Stratton 1997) These highlighted excerpts were collected and archived topic-sensitively After this process was completed we reviewed the resultant topics Where possible we used keywords to search for additional topic-relevant excerpts throughout the interview material and added them to our archive After this was completed the entire interview material was read over again to evaluate the "fit" of our topics, handsearched for additional topic-relevant excerpts, possible falsifications as well

as possible additional categories that we missed on first reading (Glaser 1967). The archived topics were rubricated in larger categories that formed the backbone of the empirical chapters of this thesis. Categories were hence not pre-determined but were rather generated from the interview material (Pidgeon 1997). During the writing process we returned to the full-length empirical material on several occasions when new questions presented themselves. Finally we re-read the full-length transcripts after the first draft of the empirical chapters was completed to evaluate its representativeness. We preferred this circular method in spite of it being a rather laborious process. Alternatively we could have used "attributional coding" of excerpts in the text with one of many commercial software programs available for this task (Stratton 1997). We preferred this methodology however since we feel that it likely increases knowledge of and affinity with the interview material since the interpreter must go through the full-length material several times. Of course this methodology would not have been possible if the size of our empirical material was greater than it was.

The character of our final text is as hybrid as our analysis suggests. Hayes suggests four types of presentations on a continuous scale ranging from pure "description" on one end to "speculative" on the other (Hayes 1997). We initiate each chapter with a rather descriptive yet thematically organized segment, strongly organized around respondent citations. The conclusion of each segment and the discussion of each chapter are rather "speculative" however since they typically do involve "high-level abstractions" with clear back-reference to theory and investigator interpretation. This necessarily implies that these segments in particular explicitly involve the author to a large degree, which the reader is advised to keep in mind. We agree with Pidgeon however that this approach does not undermine the qualitative approach necessarily since to make sense from qualitative data "the researcher needs at least some theoretical resources to begin the process of interpretation and representation" (Pidgeon 1997; Gadamer 1972). We also feel that interpretation does not necessarily imply unacceptable bias (De Boer 1988). A "good" interpretation is one that is born in dialogue with the empirical material rather than forced upon it by the interpreter (Wever 1997). Needless to say, we have strongly aimed to realize the former by repeatedly returning to our empirical material to check on "fit" (Glaser 1967).

We conclude with some remarks on the background of the author casu quo interpreter of the empirical material. The author is not deaf himself and had no children at the time that this thesis was written. This implies that he could not resort to personal experience when writing this text. The author is a physician with a social science background. He previously conducted a qualitative study on and published about the experience of people with a physical disability (Wever 1997). Though the author is currently employed as an Otolaryngology trainee at the Nijmegen University Hospital, the AZN-IvD implant team never interfered with the content of this thesis. Finally it is mentioned that the author was born to a multi-ethnic family, grew up in a strongly multi-cultural society and is a native multilingual. During his childhood and adolescent years,

he moved 7 times to 5 different countries This may have influenced his views on minorities in general and his view on (value of) ethnic identities specifically

Quantifying results

We will provide no "hard data" in this thesis Rather we intend to describe what we found to be general trends in the interviews The use of hard data could falsely induce a quantitative impression Still to be informed about the number of respondents who actually represent a specific statement does add to the translucency of the study To accommodate this, we will operate quantifications and we will mainly do so in one of two forms The first form is to actually list the individual excerpts representing a specific statement In some instances this will lead to redundancy In such instances we will at times use semi-quantitative ordinal concepts such as "all", "most", "some" and "few" (Hayes 1997) As a global guideline we will use "all" if literally all respondents expressed a certain opinion Perhaps not all respondents did so word for word, yet in all interviews statements related to that opinion were identified We will use "most" if we consider a certain opinion to be a general trend, without necessarily satisfying the prerequisites of the concept "all" This implies that we found statements expressing that opinion in a majority of respondents and in addition did not find evidence for the opposite in the remaining group of respondents If evidence dismissing the opinion in question was found in at the most 3 respondents, we persist in using the concept "most" yet will provide the opposition statements as well Finally, both the concepts "some" and "few" will be used when at the most 3 respondents expressed a certain opinion

Selecting excerpts based on illustrative power

Not all respondents may have constructed a *cohesive* narratological framework encompassing their experiences (Hardwig 1997) For some respondents, the research-interview may represent the first opportunity in which they are expected to clarify their motives in a cohesive fashion Others however, may have done so extensively It is for this reason for example that some qualitative researchers have argued that in-depth interviews may have a "therapeutic" effect on respondents What respondents say may for example tell us something about their cognitive abilities, their character, their social environment or their access to literature Qualitative analysis of narratives concerning motives almost immediately represents a bias for coherent narratives, perhaps also intellectual narratives This implies that those who provide such cohesive narratives may be attributed more value than those who do not Indeed, citations are likely selected on their power to illustrate a certain position or experience

It may be that a quantitative assessment of the frequency of certain positions or statements in itself may not be the most credible for facilitating an understanding of the

motives of parents. It may well be that while a minority of respondents is accountable for a specific statement, this statement in itself is highly valid nonetheless. What should be done in such a circumstance however is to illustrate how statements made by other respondents can be perceived as expressions of statements made by a minority of parents. This inevitably involves a "qualitative leap" by the researcher however, which implies that interpretation by the researcher is essential in linking such "satellite statements" to the central statements really.

It may even be the case that certain thoughts, which are considered crucial, are not expressed verbatim by any respondent at all, making the "central statement" the responsibility of the researcher primarily. In either such case, no evidence was found against such positions or experiences - neither concretely nor through a qualitative leap -, unless discussed differently. Yet even in such circumstances validity of the argument may be provided by establishing detailed and convincing qualitative leaps between what was actually said and what these narratives are believed to signify. Equally to literary critique, interpretation is therefore to be considered a central element in this analysis.

Respondents may provide a series of motives for their actions that in themselves are not catagorizable under one coherent theme. Though these motives themselves are open to empirical description of course, the empirical material may not always provide solid enough a basis to establish hierarchy of these motives, "weighing" them so to say. One sentence, an intonation or expression may provide more information than quantitative scoring of frequencies. For example, on inquiring about experiences with deaf institutes one parent replied: "What are we going to do now? Are we going to open that cesspool?". The tone of such a relatively simple statement may provide valuable information on establishing hierarchy. One of the problems of quantitative analysis is that it restrains itself to "flat" de-contextualized expressions. The risk of a drifting towards an overly rational cost-benefit analysis would be unacceptably great (Nussbaum 1998).

A specific yet relevant version of this latter problem is that narratives may not provide the sensitivity needed to discriminate between "cardinal" motives and "secondary" motives or socially desirable motives (Gresnigt 1973). We agree with Arras here that not every narrative has an equal value from the perspective of an ethical inquiry (Arras 1997). What we are primarily interested in here is an inquiry into the process through which parents make decisions, not how they think others would like them to make decisions. Admittedly, the two are unlikely to be sharply demarcated and may well be related. Though we recognize this and will explicitly include the interaction between "internal" and "external" motivation in our inquiry, we persist in the distinction between the two as it is believed to be sensible theoretically and particularly fruitful in the context of this study. Let us attempt to shortly explain this latter point. Parents of deaf children move within a highly opinionated environment, which often provides strong and coherent moral narratives, yet it is far from certain if these narratives cover the breadth and depth

of parents' authentic personal motivation. An example of this concerns the choice for Sign language. Authorities for example inform many parents that Sign language is the "mother language" of their deaf child. Consequently when asked about their motives for choosing for a sign environment, parents may reproduce this argument. While the concept of mother languages alludes to linguistic theory, it is questionable if parents indeed base their decisions on such an abstract philosophy. Sometimes tenacious inquiry may reveal the superficiality of such a motive, which may facilitate in identifying an answer as a rationalization, as "socially desirable" or as a moral "filler" aimed to seek shelter in moral convention. Yet in other instances parents may well be able to provide detail. In the latter circumstance however no guarantee is provided that such a factor indeed contributes to understanding the parental decision making process: it may for example be confounded by parental intellectual inquisitiveness or "verbalization capacity" (Gresnigt 1973). It could well be that the effective substructure of the argument of mother languages, that is the structure which makes the argument work, is located in a much more moral or emotional domain rather than the cognitive domain which linguistic science represents. Another example in a different context may explain this position further. Cancer patients who apply for experimental chemotherapy may be provided with motives by their treatment team. They may for example be told, if the information is correct, that the treatment facilitates the development of a potential cure for future generations. The reproduction of such altruistic motives in an interview setting may however provide more information on how the treatment is legitimized than on the authentic motives that led to the decision to undergo such treatment.

To differentiate somewhat, a distinction will be made between "early" experiences and "later" experiences, which reveals the presumption that the merging of "authentic" and "acquired" motives through exposure to meta-narratives may increase over time. This distinction was implemented in the interviews themselves but will also be encountered in the structure of this text. An explicit attempt was made to draw parents away from the general context in which decisions are embedded in their deaf environment, hence drawing them away from the discourse encountered in for example deaf literature. Starting with early experiences had the strategic effect of implementing this intent. It was found that quite a few parents initiated the interview with a monologue on cochlear implants. Typically, the nature of this monologue situated itself in the middle of the public debate which surrounds cochlear implants today. Perhaps this was because the decision was one they made quite late in their career as parents of a deaf child, in times when they had already been exposed to the medical and political construct of the debate. Alternatively, and perhaps more plausibly, it may be argued that it revealed respondents' expectations of the interview. As said, the cochlear implant debate has evolved into a deeply political debate indeed and it appeared as if some parents, both cases as well as controls, initially desired to express their public position vis-à-vis this debate. This experience was particularly strong in interviews with those parents who had actively involved themselves in the public debate, for example by taking seat in advocacy groups or by adapting other formal or informal public roles. Redirecting the interview to

early experiences however, by asking parents to relate on their experiences encircling the diagnosis, typically resulted in a definite, sometimes even startling, change of tone and content, much closer to the private domain. In most cases, once this was established it could be preserved throughout most of the interview, though the political level was included in the interviews as well.

Having said this one should be much aware of the pitfall of qualitative research that we discussed previously. The risk of producing theories which represent the inner - egocentric - state or intentions of the investigator more than the concrete experience at hand - van Tongeren (1996) speaks of subjective illusions - appears all to real, in particular when the subject of the study is controversial and politically loaded such as the subject of this study (Hakuta 1996). While taking a hermeneutic approach may indeed reduce this risk, it does not eliminate it all together. In particular if the distance between the "theoretical construct" and the concrete experience is large, the opportunity for control is increased. It appears that some social scientists have taken the qualitative methodology as a legitimization for launching profoundly theoretical interpretations. Rorty suggests that a strong preference for theoretical abstractions and a neglect of concrete situations has become an ingredient of the paradigm of some social sciences (Rorty 1998a). He suggests that the status of complex theoretical arguments in general, the potential of such an approach to distinguishing oneself from empirical-based sciences and the persisting romantic belief in "deeper meaning" may explain this preference. In his search for a collective conception of fairness Rawls equally understood this risk. Since Rawls departs from the idea that any collective conception should be subject-based, he rejects any distant theoretical conception. Hence he concludes that "comprehensive philosophical and moral doctrines...cannot be endorsed by citizens generally, and they also no longer can, if they ever could, serve as the professional basis of society" (Rawls 1993). To compensate for this liability somewhat, we have structured the text in an increasingly analytical fashion. The most abstract hypothesis will be presented towards the end of the text. In addition, preliminary hypothesis will be identified as much as possible. It is noted that the reader should keep the objections that were made in mind, hence be aware that the author of this text is not "absent" from the meaning attributed to parents' narratives. Hence it explicitly cannot be our intention to provide a comprehensive view. We agree with Rawls that, taken these objections in mind, such a view would be highly ostentatious as well as pragmatically unfit to promote debate (Rawls 1993).

Conclusions

A broad literature review based on a wide range of resources was executed as an orientation on the controversy over deaf education in general and cochlear implants specifically. In addition leaders in the field were consulted and we sent out a call for suggestions to all regional Deaf centers in the Netherlands. Based on these efforts we

identified foreshadowed problems and formulated a checklist for the interviews. Inclusion and exclusion criteria were defined based on the need for a more or less homogeneous study population. It is our opinion that the controversy over pediatric cochlear implantation has mainly focused on the case of otherwise healthy pre-lingually deaf children. This led us to exclude parents of deaf children with certain additional disabilities, most importantly those suffering from Usher syndrome. The rationale behind excluding children with Usher syndrome was that the motives to implant these children are likely rather incongruent with the issues raised in the cochlear implant controversy. It has also led us to exclude parents of children who became deaf after the age of three, since the prospect of developing spoken language skills are assumed disproportionately large in this group, again causing an incongruence with the main issues in the cochlear implant debate. Pre-lingually deaf children implanted after the age of 10 were also excluded from this study since it has been shown convincingly through technology assessment trials that these children have very little prospect of developing spoken language skills and many implant centers today hesitate implanting candidates fitting this specific profile. Other factors that may impact cochlear implant outcome, such as partial electrode insertion, were considered intrinsic to the implant procedure and were therefore not considered as an exclusion parameter.

We wanted to illuminate experiences shortly after the implant procedure as well as those of parents with considerable cochlear implant experience. In order to achieve this we selected parents from both the "experienced" as well the "inexperienced" group. We selected the former based on implantation-date rank. Taking into consideration the above mentioned criteria we invited 12 suitable parents, all of whom were parents of one of the first 23 implanted children by the AZN-IvD implant team. Eleven parents consented. Most of their children became deaf as a sequel to meningitis and the average age of implantation was 6 years and 5 months. The "inexperienced" group was selected from the most recently (< 2 years) implanted congenitally deaf children in the AZN-IvD cohort. We chose congenital deafness as a criterion given the bias towards meningitis in our "experienced" group. Nine parents were invited of whom 5 consented. Seven controls were selected based on the same criteria as depicted above. It is estimated that our respondents represent 5-8% of all Dutch parents of single-handicapped profoundly deaf children in the age group of 4-14 years of age. For specific characteristics we refer to the tables in this chapter as well as the appendix.

All case-respondents were invited to participate by the AZN-IvD implant team to safeguard privacy and all respondents received adequate information on the study design and objectives. Consent was obtained in writing. Interviews were typically 90-150 minutes in duration and were recorded on audiocassette. An interview schedule was used as a general guide throughout the interview, though we sought an in-depth, open and conversational atmosphere. Full-length word-processor transcripts were obtained. The data was securely filed electronically at the Free University department of Philosophy and Medical Ethics. The analysis was hybrid though mostly bottom-up and circular, the

latter implying continuous movement between the actual empirical material and interpretations. A final check on "fit" was performed after the first draft of this thesis was completed.

Conforming to the qualitative design of this study and the small number of respondents, we will not provide numeric data in the presentation of our analysis. Still, it is likely that we selected excerpts based on the eloquence and analytic potential of specific respondents. In itself this need not be a problem as long as two conditions are met. Firstly, selection of citations needs to be translucent. To avoid a skewed presentation, based on a minority of respondents, and to increase translucency we will use semi-quantitative ordinals in the text. In some cases we will list all relevant excerpts. In other cases we will use ordinals such as "all", "most", "some" and "few". Second, it needs to be established that the narratives by those "left out" do at least not challenge the tenor of the selected excerpts.

Analyzing qualitative empirical material requires analysis and thus interference by the author almost by definition. We do not feel that this jeopardizes this kind of research though it can certainly be a source of noise. Avoiding such interference by sticking to the empirical body closely in our opinion implies a missed opportunity to organize the empirical material more cohesively. As such critical scrutiny of what parents said was not avoided, though we constantly re-checked with our empirical material to avoid subjective illusions or "violent" interpretations.

PART II

CHAPTER 3 – EARLY EXPERIENCES & DECISIONS

INTRODUCTION

In this chapter we will discuss parents' earliest experiences with their deaf child Early experiences are defined as all relevant experiences that parents go through prior to and directly around the time of the diagnosis The lower limit of this period is marked by the (sometimes retrospectively reconstructed) onset of deafness For parents of a child deafened by meningitis this equates to the moment at which the child fell ill For parents of a child with congenital deafness it equates to the birth of the child The upper limit is set somewhat artificially at "several weeks" after deafness was confirmed The period covered in this chapter embodies several landmarks of importance it includes the time of unconfirmed deafness, the diagnosis and the period shortly after when parents are to develop preliminary strategies We have divided this chapter in three sections, the first discussing the experiences prior to diagnosis, the second discussing the diagnosis itself while the third discusses the period shortly after the diagnosis was established

EXPERIENCES PRIOR TO THE DIAGNOSIS

Introduction

Meningitis is a severe and potentially life threatening disease that still affects many people each year The incidence of the disease is about one in 10,000, 75% of which are children under the age of 12 The disease is often a sequel to a bacterial respiratory tract infection such as otitis media, sinusitis and pneumonia and consists of a secondary infection to the meninges, which inflicts severe systemic and neurological symptoms within 36 hours of onset The prognosis of meningitis is dependent on the pathogen involved Arditi reports on 180 children with Pneumococcus meningitis and found a mortality rate of almost 8% while 25% developed motor deficits and 32% moderate to severe sensorineural hearing loss (Arditi 1998) Taylor has reported 12% sensorineural hearing loss in the acute phase of Haemophilus Influenza-B meningitis (Taylor 1998) Admiraal mentions 31-51% hearing impairment in Pneumococcus meningitis and 3-16% in Haemophilus Influenza-B meningitis (Admiraal 2000)

The incidence of congenital deafness is not precisely known As mentioned previously, Davis reports that the annual incidence of hearing loss in excess of 100 dB is 24 per 100,000 live births or about one in every 4200 newborn children (Davis 1997) Most cases of congenital deafness are believed to be genetic in origin (21-48%), acquired in-utero (for example rubella) or around or shortly after birth (for example premature infants hospitalized on a neonatal ICU) (27-48%) while 10-40% is of unknown origin (Admiraal 2000) If the cause is genetic, inheritance is most likely non-syndromal autosomal recessive This latter pattern of inheritance implies that neither parent is likely to suffer from deafness It further implies that neither parent is likely to spring from a deaf pedigree Finally, this form of genetic deafness is unlikely accompanied by other symptoms Some forms of genetic deafness are syndromal however Usher syndrome, Branchio-Oto-Renal syndrome (BOR), Treacher-Collins syndrome, Pendred syndrome and Stickler syndrome are just some examples of syndromal deafness (Admiraal 2000, Gorlin 1995) The incidence of additional defects or disabilities in children who acquired deafness in-utero or perinatally is presumably higher, up to 67%, and may consist of cognitive deficits, ocular problems, systemic abnormalities and neuro-psychiatric disorders (Admiraal 2000)

In this section we will discuss parents' experiences prior to the diagnosis The fact that a diagnosis is lacking does not imply that the parental experience is irrelevant this period marks the beginning of parents' experience with deafness and as such should be considered quite significant indeed (Gresnight 1973) Since a diagnosis has the inherent capacity to "span" heterogeneous circumstances under one experiential umbrella, it seems reasonable to assume that as long as such a diagnosis is lacking experiences are likely related to the specific local circumstances rather than to social and or medical

scripts encoded in a diagnosis. Since these circumstances are likely variable, so are the experiences. One such difference, which we discussed previously, refers to the status of the disease. The circumstances accompanying deafness as a sequel to meningitis are quite different from those accompanying congenital deafness. Meningitis is an acute, life threatening condition. Congenital deafness is not preceded by such an episode, although it may be accompanied by additional medical conditions. Indeed, if the experience of parents of children deafened by meningitis and those of congenitally deaf children deviate at some point in time, it is likely to be in the earliest days of their experience. While the "end result" may be the same, namely "deafness", the path to it certainly is not. As a result we will make a distinction between meningitis and congenital deafness when discussing experiences prior to the diagnosis.

Experiencing meningitis

The story parents had to tell often began with the illness episode that caused their child to lose his or her hearing. Usually a single probing question was enough to lead parents back in time and most parents narrated emotionally and extensively about this experience. Parents recounted the events vividly, in detail and full of emotion. Indeed, many parents said that it felt "as if it happened only yesterday":

I: When did it happen, how old was she then?
M: She still had to become three, so.
F: October
M: It happened in October.
F: October
M: Just before her third birthday.
F: Yes
I: Do you still remember what happened?
M: Yes, very well, everything...
F. Yes, it is ..
M: Yes, it is as if it happened yesterday. Yes, you do not forget it, no . (C4ab)

F: I still think about it every day, really. Strange, don't you think? I will never forget it. (C6)

In most cases the child became very seriously ill after what initially seemed like a benign upper airway infection.

M We thought he was getting the flu. He was going to a day-care center at the time. I kept him at home for a day and the next day he seemed better already, so I took him to the day-care-center again. But when I picked him up that afternoon I thought: "this is not good!" He got sicker and sicker in the sense of vomiting, headache...(C12ab)

In many instances, not only parents were confused over the course of the child's illness. Quite commonly, the consulting physicians also "underrated" the severity of the child's condition. Surprisingly, in almost all cases the consulting physician was a substitute and the diagnosis was not established at the first visit. The next excerpt is characteristic:

> *M. We visited the family physician that day and called him again that night. At one moment he had a 41.5° fever...The doctor did not want to come, so I visited him. He just prescribed some paracetamol, that was it. The next day we called for a doctor again, and he also said "well, he does not look that sick". (C12ab)*

It often was not until the child developed serious neurological symptoms that he or she was sent to the pediatric ward of the nearest hospital:

> *M: Her eyes were turning away all the time. At one point she started to vomit explosively. She was grinding her teeth and was delirious. That is when they too thought it was time to admit her to the hospital. (C12ab)*

> *M: When we reached the hospital she had respiratory arrests. It was real scary. (C10ab)*

In many cases the child's illness was so severe that parents feared that he or she would not survive the episode. The medical staff sometimes confirmed this fear:

> *F: They told us that we needed to realize that she could die. I will never forget that. It was 3 o'clock in the afternoon. I will never forget that.*
> *M: She was in a coma and they said that we needed luck for her to survive. [...] We sat by her bed for 48 hours straight.*
> *F: There was a nurse all the time, because, her heart would regularly stop beating and such...*
> *M: Every time that she moved, the stickers would get loose and the alarms would ring...I would sit up straight! (C7a)*

> *I: Was there concern about her life at any time?*
> *M: Yes, it was really...I still recall the first night when the doctors came by and said. "she is very seriously ill." Well, that gives you the shivers. Take that from me... (C10ab)*

> *M: She was so sick you know, we really thought that...at least a few days, that she was not going to make it. [...] The first day when I went home in the afternoon, I - I know it sounds strange - I even called the funeral home. (CO4b)*

Most parents had some prior knowledge of the potential hearing injury induced by meningitis. For some, this had been part of their original medical knowledge. For most however the medical team first communicated it to them during the hospital stay of their child. Alternatively family members informed them.

M. Well, I still remember very well that my brother came to the hospital and said: "wow, she could become deaf or blind..." I was completely unaware of that. (C10ab)

Hence most parents were aware of the possibility that their child could become deaf. It appears reasonable to assume that this knowledge sharpened their observations. Indeed, parents often sensed that something was wrong with their child's hearing early on, often as soon as the acute phase of the disease had passed or when pharmacological sedation was reduced or withdrawn (Becker 1976). The most common trigger was the realization that the child did not respond to sound adequately as the following excerpts illustrate:

M. The ICU consisted of little rooms, all of glass. When I knocked on the glass before entering she just kept looking outside I knocked again...then it suddenly struck me: she does not hear! (C9a)

F: I entered her room in the morning. "Hello", she was sitting with her back towards us but she did not respond and that is when I noticed it. I tried again, louder this time. "Good morning", still no reaction. Well, at that moment a little part of me collapsed, I thought: "this is not good". (C4ab)

F: Well, we noticed that she did not react to sound. It used to be the case that when we opened the door to her bedroom that she would raise her little head immediately After her illness, even a nock on the door would not achieve that! (CO4b)

Yet, altered expressive language behavior also provoked concern, particularly in children who became deaf relatively late: the older the child was at the time of the meningitis episode casu quo the more he or she had mastered oral language, the more obvious the change was. Alarm arose by contrasting the emerging situation with the image parents held of their child before he or she fell ill. Expressive language behavior includes both quantitative and qualitative components. Hence, language behavior can deteriorate both by a reduction in language production but also in the quality of language. Both occurred.

M: He was in the ICU for some time, and then medium care and he slowly woke up [out of his coma- ccw]. If I recall it well, the first thing he said was "Papa", but it sounded very differently than we were used to. I have a deaf aunt...and I thought, "Oh my God, he sounds just like her!" (C12ab)

M: Well, she started to speak without voice, like only moving her mouth without making sound...(C1a)

M: She was picking up words rapidly prior to her illness and I could just see it getting less. And she began speaking drawlingly. (C9a)

Some parents recounted that even though they did notice changes in their child's speech, communication was maintained surprisingly satisfactory. One case was extraordinary in

this respect: in C15 the diagnosis was delayed almost 3 years yet parents explained that typical communicative clues were lacking:

> *M: If we asked her something, she would do it perfectly. How she ever did, we do not know. I think she just looked well and knew what was going to happen. She was never upset when we showed up in her bedroom, you hear that often...(C15)*

This situation may have been the result of the development of different communicative skills, most importantly the skill to read lips or grasp communication through context. Several parents mentioned this:

> *M: Even when she was very ill, when we would talk straight into her face she would understand us, she would see our facial expressions and .Yes [...] We never experienced, you hear this from other parents, a blockade -- she did not have that (C12ab)*

> *M: Because she learned to read lips very rapidly, we thought, "she does respond to speech after all, perhaps she still hears something". She really started to read lips fast, amazingly fast. Even the nurse was perplexed and started to question herself. (C4ab)*

Additionally, some parents spoke of the unnoticed inclusion of gestures in their communication:

> *M. And we started, I notice that now too, you know we use gestures a lot in our family. We touch each other We are very southerly orientated, you could say that In addition she understood a lot [of spoken language -- ccw] hence there was interaction on both sides. We never experienced problems, no (C12ab)*

The oldest children sometimes provided explicit clues themselves:

> *M· She had this music box...it was broken she said but it was not. (C6)*

Not sure about the merits of their intuitions, parents routinely attempted to substantiate their fears by subjecting their child to provisionary testing methods, such as clapping or talking loudly outward of the child's visual reach (Spradley 1981).

> *M: We started to test her, at a certain moment we would throw toys on the floor to see [if she would react -- ccw] (C12ab)*

The result of this testing did feed concern but rarely led directly to an objectified diagnosis as parents were inclined not to insist with their findings towards the medical staff at that time, consumed as they were with the compound situation.

> *M· I did not think about it much further. I was very happy you know, because she was out of her coma and things seemed to be going so well. (C12ab)*

F· You're not thinking about that [hearing loss-ccw] at that time You're just glad that she is out of her coma.(C6)

The episode of meningitis was a severe one indeed and consumed much of parents' emotional reserve and attention. In addition the condition was typically not sharply demarked in time, but rather spread out over a recovery period of several weeks, which may have blurred parents' focus. Otherwise phrased, it may take time to modify one's perspective from one "fit" to the acute life threatening event to one "fit" to the (chronic) post-meningitis recovery period.

M· How do I explain this? It is very, very difficult to establish that someone is deaf if she moves from a coma to normal...
I: Do you mean that you have to go through a sort of gray area. .?
M: exactly. (C12ab)

Furthermore, when parents finally did reach the conclusion that something was wrong with their child's hearing, the presumed severity of the condition was sometimes trivialized (Mattson 1972; Philp 1982).

F· Well, you always have that hope remaining, that it is less severe than you fear...(C9a)

When presenting their concerns to the medical staff, the latter sometimes played down worries (Isarin 2002):

M. It was denied time after time. And that was welcomed, like "our concerns are wrong, thank God". The doctor said that it was all-OK and we accepted that all to easily. (CO6b)

I: She was 4 months when she was struck by meningitis?
M· Yes, and over the next year everyone kept saying, "oh, those concerned parents, everything is fine" (CO6b)

M· At a certain moment we approached the pediatrician and said, "it is like she does not hear well". They said that after meningitis one had to wait six weeks for recovery and only after that diagnostics were sensible...(C1a)

As a result quite a few parents felt some resentment towards professionals involved with their child up to the diagnosis, such as the family physician, pediatrician and otolaryngologist (Hall 1988; Isarin 2002).

M· He [pediatrician] did not investigate it at all. He did not refer us to an otolaryngologist either. Finally he referred us [to a university ENT department – ccw] saying "they won't find anything either but at least you will be sure". So we went to Nijmegen and it turned out that she was deaf The response of the pediatrician? It was like "so what, even if you had known it a year earlier it would not have made a difference". He never apologized for the fact that he was wrong. (CO6b)

> *M: I really felt that all those physicians that we had had over the course of a week or two had abandoned me. Mistakes and blunders were made From that moment on I decided never to trust a doctor again but to navigate on my intuition foremost. (C12ab)*

The experience left at least three parents embittered about the medical profession (CO2, CO6, C12ab). C12ab proclaimed "never to trust a physician again". CO6 contemplated legal action against the consulting GP. CO2 had such a negative memory of the hospital experience that she declared even not to want to be "placed on a bier" at that institute.

As a result, delay occurred in referring the child to a diagnostic center, though this delay was generally rather limited. In 12 meningitis subjects the average referral delay was 6.7 weeks after onset of meningitis. Age influenced the referral delay, as the average delay in subgroup-A (children between 2-3 when struck by meningitis) was only four weeks. Taking into consideration that most children were hospitalized for 2-3 weeks, this implies almost instant referral for the older children. One case (C15) experienced a considerably longer delay of 33 months. The age of onset of deafness of this child was the youngest in our meningitis series (3 months), which may explain the delay to some degree. Child rank does not appear to have impact on referral delay.

Experiencing congenital deafness

In contrast with parents of meningitis children, the story of these parents lacked a distinctive beginning. There was no severe illness preceding the awareness of a hearing problem and overt physical problems were often lacking with the exception of one case (C16) with severe and life threatening cardiac disease, which resulted in a 30-month diagnosis delay:

> *M. My mother would hold him in front of the window and would say, "He looks blue". If he cried he would become dark blue really! He was operated and we were allowed to visit the ICU. I did not recognize him, his hair looked white...he was that blue. His oxygen was 38%, so not good at all. He could have died...so that is why we did not really notice his hearing problem Perhaps if he were a healthy boy we would have noticed something earlier. (C16)*

One should take into account that most other parents had given birth to and were the parent of what they believed was a fully healthy baby (Darling 1983; Beck 1996) and were hence likely not as keen nor focused in their observations: they had no reason to look for something.

> *M. I had no suspicion at all. I had not reason to...it was just a fine child. (CO7)*

Nonetheless, most parents did experience a threatening presentiment well before their child reached his or her language age (Eldik 1998; Beck 1996; Isarin 2002). In most

cases this presentiment was based on the fact that other unusual conditions accompanied deafness, even though these conditions were not manifestly physical. One case was particularly illustrative:

> *F: From the beginning we had the feeling that she was from another planet, because she was so different from her sister. Really strange, since their physical appearance is so similar. [...] But we felt like: this is really a different child She really radiates a distinctive deaf identity so to say. The way she looked real directly and, a strong personality, making things very clear. We always felt that. [...] Also the way that she communicated, the clearness of her gaze. It made you feel like: this is a different way of making contact. That really struck me. Very different than her sister. [...] The eldest can also look at you very well, but does not have that piercing gaze by far ... (C13)*

Even so, the direction of parents' presentiment was commonly rather diffuse and did certainly not point towards a hearing disability. If anything, the opposite appeared to be the case: the presence of additional abnormalities drew attention away from the hearing disability. In other words: if parents were looking for something it was not deafness that they were looking for. Balance and motor problems blurred the auditory handicap:

> *M: She had terrible motor functions, was very hypertone, would not sit, did not walk or crawl and was quite temperamental. In sum, there were lots of problems all the time, amongst which her hearing and lagging speech. We were put on a wandering hike because of this .. (C13)*

> *M: He stretched his body a lot, he would be all stiff then. That scared us. [...] He would stretch and could not sit up. He was one year old and still could not sit-up, he would fall over. His motor function was terrible...yet we thought it was something physical, but his hearing we did not question for a second. (C14b)*

More commonly however parents noted that their child responded inadequately to sound.

> *M: At a certain moment I became aware of the fact that she did not respond immediately when I would speak to her or that she did not move when I entered the room. (CO7)*

> *F: Yes we had our suspicions when he was about 7 or 8 months old. But we did not know how bad it was*
> *M: Yes, yes*
> *I: How did this suspicion arise?*
> *F: We noticed how he did not respond.*
> *M: There was this thunderstorm one night.*
> *F: Thunderstorm yes*
> *M. A door slammed real loud, we had a window open, the door of his bedroom slammed really loud and we thought "oh no, oh no"*
> *F: It startled us but the child just kept sleeping*
> *M: The child just kept sleeping and we thought well...*
> *F: That is not normal! (C8b)*

Yet it appeared that the lack of sound-response was not always as clear as one would expect (Beck 1996):

> *M: It is difficult to detect. If I look back at it, well he was a smart child. You remain in doubt for an extended period. If he was playing in the kitchen and the door would open, he would respond But it was because he felt the airflow, not because he actually could hear the door open. If he was crying in his bed and I went upstairs, he knew you were coming, he could sense the vibrations of the stairs. (CO5b)*

These observations usually became more and more concrete as the child grew towards language age. Later on in time, the lack of language development itself further fueled concern. Conforming to the findings of Shah, the lack of spoken language development after the first year of life often is the final trigger to seek professional counsel (Shah 1977; Becker 1976). Alternatively, the Ewing test sometimes identified problems:

> *M Well, he had to do the Ewing test. He was sitting on my lap while they were testing him. He was all concentrated. They would horn loudly behind him but he did not respond at all. [...] We were sent to an otolaryngologist within two weeks. (CO5b)*

> *M: After two failures on the Ewing test it was suggested that it may be a good idea to visit the audiological center (CO7)*

Yet in one case (C13) a negative Ewing test did not speed up the diagnosis. Concurrent serous otitis media seemed to have blurred the situation.

> *F: They both [deaf child and hearing sister] flunked the Ewing test miserably. But they were suffering from runny noses and had ear problems In January, when they were 12 months old, both got ventilation tubes and an adenotomy, which improved their situation considerably. (C13)*

A delayed language development was sometimes attributed to conditions that accompanied deafness, most vividly in C16:

> *F: When he did not speak at two years, the cardiologist argued that it was because he went through so much He was one year behind, but he [cardiologist] felt it would become better once he [son] came in calmer waters. (C16)*

Yet more commonplace explanations were also sought. Similarly to what we described in C13, some parents suspected that their child suffered from serous otitis media, a suspicion that was sometimes supported by their physician:

> *M: We visited our otolaryngologist . he suggested that she may suffer from fluid behind the eardrum (C2b)*

M. At one point he had recurrent ear infections. He was prescribed one course of penicillin after the other; he had fluid behind his eardrums. At nine months he had the Ewing test. By then I was convinced that he did not hear well but thought, well they will just give him ventilation tubes and all will be well (CO5b).

Parents sometimes hypothesized that what they noticed fell within the "normal range".

M: I felt that this was part of her singularity. She just had her own little world. (CO7)

The degree to which parents noticed something unusual may be dependent in part on the rank of the deaf child in the family. Of 10 congenitally deaf children in this study, 5 were first-born children. If a deaf child is first born, a lack of an available reference frame may cast a cloud over observations (Beck 1996):

M: We felt that something was not right, but she was our first child so you think, well maybe she is just a little slow with things. But she did not react to toys when she was 6 months, did not respond to sound, reacted with scare when we stood at her bed, like "oh, there is someone there!" And she slept through everything. Sometimes there would be a lot of noise and we thought how strange that she does not wake up! But we thought, well that's normal, a very calm child who sleeps through everything. (C2b)

F: The child developed slow but eh, because it was our first child and you are not really focused on that. (C8b)

To compound things even further, it appeared that some children did actually engage in expressive language behavior.

F: He made sound as well.
M: Yes, he made sound. [...] A lot of sounds. He would babble a lot, which made things hard for the otolaryngologist. (CO5b)

In spite of a delayed language development, some parents did not seem to be aware of this. It appeared that alternative communication patterns and the development of other "senses" drew parents away from the conclusion that something was wrong (Beck 1996):

I: You did not consider it [hearing loss - ccw] for a moment?
M Absolutely not Because she had such an alert expression. And you could communicate with her physically one way or another. Sure, I would talk to her and she would babble back to me She certainly did make sound, like "nom, nom". (CO7)

F. In retrospect we noticed how we spoke less with her [compared to sister] when changing her diapers.
M: I felt really guilty about that- that I never had the need to talk to her.
F: It is really strange that you also do not respond [when child does not respond]. It is sort of an automatism, if a child gives no verbal signals you don't either. Real strange. (C13)

M She could make herself clear impeccably, that was the odd thing
F· Really impeccably, by pointing, by looking.
M: By pulling.
F. A friend of ours once said: she is just like a little Chinese empress. One look is enough; you know exactly what she wants (C13)

Sometimes others were the first to detect something strange:

M. When she was seven months old we went on vacation with friends. They had a child 8 months before. So the four of us spent time in a cottage. At a certain moment my friend said· I think something is wrong with her, she responds so differently compared to our child. [...]
I: Did you have doubts yourself?
M· No, not at all! (CO7)

Most parents did not persevere with their early presentiment in the sense that it took quite a while before they first consulted a physician. The "strange situation" did persist of course and consequently caused distress in parents as they came to question themselves:

M: It was rather scary. I was afraid that I did something wrong or something like that
I: How so?
M: That it is your fault that the child is not responding, that you are doing something wrong. [...] It makes you very...it causes doubt. (CO6b)

Eventually however, when the condition persisted and concern accumulated, parents presented their worries to a health care professional. Not surprisingly, the delay in referral to a diagnostic center was considerable. In addition to parental delay, parents related of a physician-delay (Paul 1993; Coplan 1987). It typically took more than one visit to the family physician, community health services or otolaryngologist before concerns were taken seriously. Complaints were regularly trivialized and worries dismissed, a finding which has also been reported by a recent Gallaudet University survey (Menzano 2000; Barber 1963; Simons 1987; Darling 1983):

M· The pediatrician told me that I was a hysteric mother and overly concerned, needed to go home to open a bottle of champagne because there was nothing wrong... (C13)

The average age at referral was about 58 weeks. Surprisingly, the three respondents with more than one deaf child (CO3, CO7, C8) reported that even with their second deaf child, the diagnosis was rather delayed. Also remarkable is that the diagnosis was delayed (22 months) in one child whose father had a medical background, which underscores how difficult it can be to detect deafness in small children with congenital deafness. The earliest diagnosis (4 months) was established in a family from a deaf pedigree (C6).

Specific issues, cases versus controls

No evidence was found that early experiences differ significantly between cases and controls. The narratives appeared rather homogenous in content. Differences appeared much more dependent on local circumstances than case-control status.

Conclusions

Summarizing this section, the interviews indicate that meningitis children fell ill after a progressive episode of what seemed like the flue. Both parents as well as family physicians were unsure about the diagnosis initially. At the end, most children became life-threateningly ill and had to be admitted to an intensive-care unit. Parents often feared for their child's life and recounted these experiences extensively and empathetically. Most parents were informed about the possibility of complications - including hearing loss - by the medical team, information that triggered them to "test" their child as soon as his or her medical condition allowed it. The older the child, the clearer it often was to parents that something was wrong as deafness induced changes in receptive and expressive language behavior. Generally some time elapsed between the moment that parents became aware of the possibility of deafness and referral to a diagnostic center. The delay in referral was about 6.7 weeks. Generally, the older the child was at the time he or she fell ill, the shorter the delay to referral.

It was found that parents of children born deaf went through a considerable time frame of uncertainty. Parents initially had no reason to suspect that their child could be deaf. Additionally, establishing deafness during the first year of life is particularly difficult because of the "natural" absence of spoken language. Parents did develop a presentiment of something being wrong, mostly based on accompanying oddities. Like parents of meningitis children, these parents also neglected their fears for some time. For the sake of completeness it is emphasized that co-morbidity was by no means exclusive to children with congenital deafness but occurred in children deafened through meningitis as well. Nonetheless it appeared that parents of congenitally deafened children were inclined to recall co-morbidity as the first sign of deafness whereas those of children deafened by meningitis were more focused on the condition itself. As mentioned previously, prior knowledge of the possibility of deafness as well as the availability of the child itself as reference frame (before and after meningitis) may explain this finding. Taking into account that communication through language does not develop until after the first year of life combined with the fact that parents of congenitally deafened children in particular often disclosed that a non-linguistic communication modality developed silently between parent and congenitally deafened child - hence masking the oral-aural communicative disability - it is perceivable that parents of congenitally deafened children were misdirected somewhat. Delay in referral of congenitally deaf children was considerable: 58 weeks.

EXPERIENCING THE DIAGNOSIS

Introduction

The diagnostic process to establish deafness at a young age is rather complicated, meaning that no simple objective test is available *routinely* to establish the extent of hearing loss in small non-verbal children. While Oto-Acoustic Emissions (OAE) is an objective test, it cannot specify hearing thresholds. Brainstem Evoked Response Audiometry (BERA) can detect perceptive hearing loss but has not been introduced as a standard screening tool in the Netherlands, even though it is used routinely by diagnostic centers. The first-line test strategy at diagnostic centers is often rather similar to the Ewing test, implying that the infant is exposed to increasing levels of sound at different frequencies while observing response. Sound is typically produced by a set of speakers at either side of the child. If the child responds correctly by glancing in the right direction, he or she is "rewarded" by a visual image projected on a TV screen located at that specific side. In the hands of experienced personnel this method provides reliable outcomes.

In this section we will describe what parents experienced at the time that the diagnosis was established through such methods. As we have mentioned, one of the peculiar characteristics of a diagnosis is that it provides certain homogeneity in experience. One key feature of a diagnosis is that it provides an experiential script: it prescribes what those suffering from a specific diagnosis are "supposed" to feel ("symptomatology"), where one is heading and hence what one can expect to feel ("prognosis") and what can be done ("therapy"). Beyond this formal medical story, it seems likely that at least the more prevalent diagnostic categories also "enjoy" socio-cultural scripts, which are likely more normative-existential in content (Wever 1997). This makes the moment of diagnosis quite interesting: it allows good insight into what "being deaf" signifies for inexperienced hearing parents, a meaning which they are likely to share with the medical and socio-cultural stories on deafness and disability.

The agony induced by the diagnosis

The final diagnosis was mostly established at one of the specialized regional audiological centers. Given the geographic spread of our respondents, the most common diagnostic centers were: Nijmegen University Hospital (AZN) and IvD for the southeastern provinces, NSDSK for the western provinces and Guyot or Groningen University Hospital for the northern provinces.

Since the children were rather young at the time of diagnosis, parents were always present in the testing environment As a result, the diagnosis was often instant

> *M I was sitting with her on my lap with two huge speakers on each side blasting a load of noise She just sat there I really felt like very confronting, very confronting you know? I knew then that she did not hear at all (CO7)*

Even if parents did not deduce the seriousness of the condition straight away they were sometimes able to derive this from the tester's non-verbal expression

> *M I recall it very well he sat at one side and we at the other He was really trying hard to find sound with her and you could just I could just tell by his look he had not even spoken yet Do you remember [to husband - ccw]?*
> *F Not really*
> *M That he was looking at us in that way, I thought Oh no (C9a)*

It appeared that, perhaps in an attempt to sooth the pain, the audiological team was sometimes vague about the diagnosis (Isarin 2002).

> *M They told us well they feel that "deaf" is stigmatizing, so they said he was hard of hearing instead But really, he is very much deaf! They were trying to be kind, not saying that he is deaf and nothing can change that But like, better use "hard of hearing" so people won't think he does not hear anything at all Give me a break! I mean, they should not beat around the bush like that deaf is deaf and hard of hearing is hard of hearing The two are different concepts (CO5b)*

> *M They were afraid to say that he was completely deaf, he said 'maybe he can do something with a hearing aid" but*
> *F Yes, they wanted to soften the message but the reality was that he was profoundly deaf (C8b)*

Many parents revealed that the final diagnosis induced profound and enduring psychological strain (Mattson 1972, Beck 1996) Parents verbalized this experience in rather cataclysmic terms

> *I What was your response on that message [that the child was deaf - ccw]?*
> *F Let me put it this way, your world collapses! At that moment, eh, it takes several weeks, months even even though we knew that things were not OK for months (C8b)*

> *I So what did you experience then?*
> *M Well, you think, "in front of which train shall we throw ourselves' That is what we experienced a little then Looking at the tracks thinking, 'shall I do it?"(CO4b)*

In compliance with psychological mourning theory, some parents expressed to have been angry, out to look for someone or something to blame and in denial (Kampfe 1989; Vernon 1984; Kübler-Ross 1969).

> *M: At first I was furious. But what else do you expect? You need someone to blame! Of course I was sad and shocked and all. But my first reaction was fury.*
> *F: It was as if we were numbed at first, you automatically go into some sort of block, not wanting to face the impact fully. I think it goes in phases In either case, we fell into a very deep well indeed. (C13)*

It has been often assumed that parents of a disabled child fail to face the permanency of the condition, at least initially. Rather than acknowledging that the disability is irrevocable, parents look for ways around this conclusion in a variety of ways (Simons 1987). Simons for example, paraphrases the mother of a child with an intellectual disability as saying:

> What I was really looking for was someone who would tell me what I wanted to hear - that it would go away. (Simons 1987, 6)

One common response in the early days presumably would be the wish that some kind of a diagnostic mistake was made. Indeed one respondent said:

> *M. Ultimately you cannot be prepared for the message [that she is deaf] It hits you hard. Our first response was that it must be because of the tests. Notwithstanding everything [CO6 had a strong presentiment that child was deaf - ccw], it is strange but that denial you know, you want to persist in the idea that, you do not want to accept it. Like eh, they did not connect the wires correctly. They did not execute the test correctly. (CO6b)*

Parents look for "cures" and search for "outs" Simons adds. Indeed, several respondents mentioned such an experience explicitly. Medical "cures" were hoped for:

> *M. When he had just become deaf, I felt like· we'll have to do something about it. Perhaps they can operate him, maybe they can do this or that. (C12ab)*

> *F· The first question was "when will she be operated?"*
> *I: That is what you asked?*
> *M: What can be done about it?*
> *F: As layperson yes, I thought: "they will have to operate it" (C7a)*

> *M: Our first question was· what can be done about it, can it be operated...[...]*
> *F: I have a brother who had middle ear disease, he has no ossicles and hardly a tympanic membrane, so I knew something. So I thought, every one is implanted these days and it can be repaired. So what are they going to do about it? (C14b)*

Several parents drew a parallel to ventilation tubes. The efficacy of ventilation tubes in curing conductive hearing loss was apparently translated to the situation of their child.

> *F: We thought, maybe it is not that bad after all. Maybe she will get ventilation tubes, they do that these days, they all get tubes and eh...[...] You think that it will not be that bad...that it really is deafness, you do not think of that. (C2b)*

If this hope was torn down, "miracle cures" were sometimes considered:

> *M: At a certain moment [after the diagnosis] we visited a clairvoyant. But he came to the same conclusion. (CO2)*

> *M: My reaction was like: I have got to go to the Philippines! 'Cause I had heard that there was a miracle doctor there You know, the kind that operates with his hands? Those fabulous stories. (CO7)*

> *M We tried the strangest things, even paranormal healers One goes real far with these things you know. (C12ab)*

In retrospect, this mother interpreted her experience conforming to Simons:

> *M. The Philippines story was of course a primary response Like, she is not allowed to be deaf. She must hear. Yes, that fits the ideal image... (CO7)*

Another mode that we encountered was to downplay the severity of the disability. Even after the diagnosis was established, parents sometimes hoped that the condition was perhaps milder than suspected or would alternatively improve over time:

> *M: You always hope that there's something left, that a hearing aid will be useful or something. You don't know how bad it is. You know so little about it you know? (C10ab)*

> *M: Finally we were sent to an audiological center and within 10 seconds they told us: "she is totally deaf". That was a serious blow because we were thinking that it would go away. (C12ab)*

The initial shock appeared to be rather *diffuse* in content however (Levine 1981), which may be related to the fact that most parents, with the exception of one parent from a deaf pedigree (C6), acknowledged that they had little or no detailed idea what being deaf entailed at the time. Even on insistence, most parents could not provide a more detailed description of their initial agony. The next few excerpts are characteristic:

> *M: It was all so strange. The next day I realized more profoundly what had happened. We have a deaf child, oh, oh, oh... (C13)*

F If I think back at the moment when we were told she was deaf, yes, surely I cried and, but without knowing why, why I was so sad (CO5b)

F Your world crumples a little I mean eh, we did not even know what the impact of deafness was on language Even so (C9a)

It hence seems that the experience that the final diagnosis invokes, is one of general and diffuse yet profound tragedy That it must be "terrible" to be deaf hence appears "common sense", so obvious that no more detailed description is required (Levine 1981). Two parents even went so far as to question the value of life for their deaf child

M I asked myself, what is worse, being deaf or being dead? (C12ab)

M At that time I also sometimes thought that maybe it would have been better if she did not survive Because you just do not know what consequences it will have for her How her life is going to be (CO4b)

Hence, the tragedy of deafness is perceived to be so profound and inexorable that these parents questioned if life with such a condition can ever yield any pleasure or quality of life. In general the answer to this question seemed to be an unconcealed "no" Unable to imagine better times, compounded by the fact that they lacked a real-life reference frame, parents were often driven to despair

M I was not used to severe handicap, with the exception of that old aunt of mine - emphasis on "old" People [with a handicap] who were really happy? I did not know any I did look for them If I did have access to such examples I think I would have been more at ease Not like "so he will be happy too" but at least there is a chance that he will be happy That was my main concern like, oh how terrible (C12ab)

F And you think this will go on her whole life right? It is not like someone who is seriously ill and recovers, this stays forever and that is a long time you know? (C8b)

I What kinds of thoughts were bothering you?
F Things you don't really think about with healthy children What is he to do with his life? What is he going to do in the future?
I School opportunities also?
F No, not that kind of specifics, just "what is his life to become?" (C8b)

I What was the first thing you thought about?
F Well, that she did not hear anymore yes And that it would have a huge impact on her entire life (C9a)

One parent couple substantiated their view of the presumed martyrdom of deafness with the next observation.

F. We have a picture that still reminds us of that period; because he sits there so silently while he was such a happy little man. You could just see him thinking, these are interpretations of course, and you could see him pondering over what was wrong. That is how we felt right?
M: Yes, I feel it was an enormous shock for him. [...] It is so striking how he speaks about that period. [...] He knows that something went terribly wrong with his perception. So he says "I was blind then". [...] He has no other memory of that period. But he does know, he identifies the house where we lived then with something that he calls "blindness". Like: something went wrong with my perception (C11)

Yet some more specific associations were also mentioned. One such utterance was the immediate awareness that deafness cuts off the very means of establishing or maintaining a relationship with one's child (Beck 1996). It appeared that this thought referred to more than the inability to develop spoken language skills alone. Perhaps because language is not an issue of direct importance in very young children, parents alluded to the pre-verbal role of sound and voice. The significance of the voice in establishing profound and intimate parent-child relationship is illuminated by these excerpts:

M: The first terrifying thought was like "she cannot hear me, I cannot tell her things, and I cannot communicate" [...] When I realized that she could not hear my voice, that was strange and very disturbing.
I: Your voice, is that...
M: Yes, you put a lot in your voice. You put a lot of emotion, certainly with babies (CO7)

M: I thought: I can never talk to him, he will never hear my voice, he will never hear songs and he will never hear. That was terrible. [...] I felt like: he is in his own world but how am I going to reach him? (C14b)

One mother literally thought she would lose her child because of deafness:

M At first it felt like we lost her the second time. The first time was like "will she survive?" [meningitis episode - ccw]. The second time was when we learned that she was deaf, we felt like "we've lost her again". Because, how do you engage with a deaf child? We had the idea that she would have to be raised by someone else, that we could not raise her. [...] And you think that such a child will have to be raised in his own world. Own school, an institute. (CO6b)

In particular mother respondents expressed to have been seriously concerned over their (in-) ability to form meaningful relationships with their deaf child (Beck 1996). This concern had both relevance to the immediate situation as well as the anticipated future and proved to be both hypothetical as well as rooted in experience. In the early phase mother respondents in particular suffered most severely from the thought that they would not be able to "bond" with their child.

M When I first realized that she was never going to hear I thought 'how am I going to teach her things?' How can I show her the world and such? I found that a very threatening thought (CO7)

A few parents did have some indirect experience with deafness One parent for example, had known a deaf boy in the past A dreadful model it appeared

M Only that boy that I knew But in retrospect it appeared that he had become deaf through meningitis and had a mental retardation but that was never told to me [ ] I always envisioned him but he was not normal (C14b)

This knowledge led this mother to equate deafness to institutionalization

M He attended IvD the entire week and only came home during the weekends so he was muffled away a bit (C14b)

Thinking of deafness was synonymous to thinking of institutionalization at least to some parents Institutionalization was associated with deeply negative emotions

M One knew about IvD right? So I said he will not go there That was my first response that old monastery Never will my child go there It is not a place for a young child to be It is like a prison (C16)

I How does that [institutionalization] make you feel?
M To run away very hard dig a hole in the woods lock the door and throw away the key! I cannot live with that thought It makes me very anxious (CO2)

M We did not get a child to put her away in an institute We would not see her anymore only on occasion That was a terrifying image to us (C4ab)

M Emotionally it is very difficult to think about that [institutionalization - ccw] that you would not raise your own child He would be a stranger to you Because they become strangers then (CO6b)

Having experienced institutionalization in the family, as one parent did, did not appear to lead to a different view on things

M She [deaf sister] attended residential school so in the family we knew quite a lot of unpleasant stories Like when she came home how nobody understood her And that she would only visit during holidays and that they had to pull her away with four people after the vacation to return Yes that was emotionally cutting (C6)

It should be noted however that Hoogeveen found that a minority of parents (35%) renounces institutionalization categorically, although it seems that parents of younger children are more negative than those of deaf adolescents, which may point to changing

standards or perhaps a time-effect – more experienced parents may grow "accustomed" to the idea of institutionalization (Hoogeveen 1998). It could be hypothesized that the group of parents rejecting institutionalization categorically is formed by the 21% of parents with deaf children attending the mainstream or schools of the hard of hearing (Eldik 1998). The most reported reasons for this rejection are to "retain the parental role" and to prevent the child to "estrange" from mainstream society and culture (Hoogeveen 1998). It could also be argued that one should interpret this experience as symbolical in addition to its verbatim interpretation: the institute may symbolize the fear of failing to establish a satisfactory parent-child relationship in its most outlandish form.

Another experience-based association made by some parents was that deaf people could not learn to speak or could never learn to speak effectively:

> *F: I had some experience with a deaf boy at our athletic club; he was completely deaf and could not speak. He could produce some sounds, but that was about it. [...] That is what I envisioned. I thought, that is the way he is going to be and that frightens you a lot. (C14b)*

> *M: They [deaf family] were very happy, I always felt that was an advantage, like; in their own way they have no problem with it and would not want it to be different. Because they even rejected hearing aids, they had tried and found it to make too much noise. They did not need it since they lived in the Deaf community. But if I looked at their level, that caused me a lot of concern.*
> *I: Can you explain?*
> *M: Yes, the only contact we had with them was like; "do you want coffee...yes nice". Very simplistic.*
> *I: Very basic communication with the rest of the family?*
> *M: Yes, since the rest of the family did not master Sign language. And neither did they, but they learned it themselves. (C12ab)*

For parents of children who became deaf after they had mastered some spoken language the agony was described in different terms. In most instances the child fell completely silent in a matter of weeks:

> *M: That is really difficult What I found difficult is that I used to have a child that was singing and chatting all day She was so aware of the fact that she stopped hearing and talking. (C10ab)*

Hence, what appeared to be a major source of distress for these parents was the rapid and massive decline of language production.

We also found that parents commonly struggled with the question if deafness could have been averted, which was of course particularly true for parents of children deafened by meningitis (Menzano 2000; Blume manuscript):

M. The biggest mistake we made is that we saw that she was terribly sick and nonetheless did not take her to the hospital ourselves when the visiting GP did not refer her.
F: You are a layperson aren't you She was having seizures and all...[...] You ask yourself why it had to happen to her. Was something done wrong? You're always searching for guilt and cause (CO6b)

M: I still have a bad feeling about that, that we were not on top of things. That feeling lasts forever you know? [...]
F It causes one to thoroughly think things through [...] Perhaps there is some self-blame in it Like; did we neglect something that caused him to fall so seriously ill? (C11)

I: Do you feel guilty?
M: Of course! Just that I was not more assertive towards the physicians, that I placed him in a daycare center - he went there three days per week and it was something which was not done in this part of the country, working mothers and all I guess it is different in Amsterdam and it has gotten better here too, but back then people would say: you are going to stay at home with your children right? It was not looked at positively. And then something like this happens, so that makes you feel extra guilty. I know it is irrational, but I felt guilty, yes (C12ab)

Indeed, Menzano and Blume also report that parents often experience feelings of guilt, wondering if they could have prevented deafness (Menzano 2000; Blume manuscript).

The exemplar of silence

"Silence" was a concept that we encountered quite frequently in the interviews, though mostly implicitly. The general purport was that parents were concerned over the fact in itself that their child had no access to sound, thus without deriving more concrete problems from the lack of sound, such as the inability to speak. While only few spoke literally about "silence", a different terminology was employed by some other (such as "soundless vacuum") while in the majority of cases these concerns could be derived from context (i.e. "He cannot hear anything anymore..."). But, what does this talk about silence represent? Why are parents concerned about silence and why does it cause them to grief?

First and foremost, the narratives on silence appeared to represent a somewhat diffuse concern originating from linking silence to suffering. It is emphasized again that silence itself was the object of concern here and not derivatives of silence such as inhibited language development. This is supported by the finding that parents did speak about silence yet had some difficulty in explaining *why* this was so worrying to them. When asked why the idea of silence bothered them so much parents did typically not reach further than the next excerpt.

F Look, a child with some hearing remains, well it at least hears something But if you hear nothing at all that is of course (C9a)

It could be argued that, given the very diffuse nature of parents' concern and their lack of knowledge about the effects of deafness on speech, this diffuse concern is related to the diffuse agony accompanying the diagnosis that we described in the previous section "Silence" in itself may as such be argued to function as the focal point of parents' sense of terribleness and tragedy

For children deafened by meningitis, silence was connoted to a sense of loss (Beck 1996)

F You know, she was hearing before and now suddenly her world was made silent I would notice that she missed sound at times
M When we would turn on our stereo she would remember that it produced music and she would look at us bewildered as if she was thinking 'hey, I am missing something' [ ] The same occurred when we took her to the carnival parade she observed all those dancing people confusedly She never actually said this, but when I explained to her why she was not hearing the sound she was accustomed to when an airplane would fly over - I explained to her that she had been sick and could not hear anymore - she looked at me as if she was now finally understanding what was wrong She wanted to hear music, put the radio on loudly but would hear nothing and would become angry 'why is it not working?' Or the vacuum cleaner, she would touch it and become angry like 'why am I not getting any sound?' (C1a)

Though these accounts represent parental interpretations of course - something most parents were well aware of - some parents did support their interpretations with additional signs, such as the child's behavior Some parents said for example that they had noticed that their child was "bewildered" by the deaf experience and related this to the sudden lack of auditory information primarily

F She was happy, positive, outgoing, a talker, loved to sing, conquering she was a bossy little girl, wanted to control things until she became deaf she became a shy little bird so her world also collapsed She would say 'Daddy you are a deaf bird' She thought we were all deaf, like not she was deaf but everyone around her! She could not comprehend it She would panic at night, waking up and telling us that she could not hear Bassie and Adriaan [a child TV duo -ccw] we had to flip the tape over, because she could not hear it and demanded to hear it She was angry and irritable, at us too like we brought her to the hospital and now she could not hear (C4ab)

Yet it appears that the explanations of "diffuse agony" and a "sense of loss" fall short of covering the full breath of the concern expressed by parents This may be illustrated through the case of music, which appeared in quite a few interviews It seems conceivable that music functions as a metaphor in this context One of the connotations of music is arguably related to positive emotional states such as joy, happiness, romance

or love (Atkins 1984). Another is its ability to sooth or provide support in times of emotional agony, which in part explains the attention psychotherapists have had for the medium of music (Brydon 1979). As such the lack of the ability to perceive of music could be said to symbolically represent the "joy of life", which a deaf child is presumed to be cheated of.

> *M: Well, at that moment I think she was very aware of like 'hey, I do not hear music and all those people are dancing'. I think that made her sad. (C1a)*

> *I: You speak about a soundless vacuum. Is that emotionally difficult for a mother, that notion?*
> *M: Yes, because you are afraid that he misses something. I loved music at that time [when the child became deaf] and thought all the time 'he cannot enjoy that'. The same with voices and you think that will make him very unhappy (C12ab)*

What emerges from these excerpts is that parents worry that their child will miss something and that this "something" is related to joy.

An alternative explanation is that the inability to enjoy music says more about the inner state of the parent than of how he or she perceives of the child.

> *M: I was very into music you know. I stopped playing the flute immediately. I could not listen to music anymore. (CO3)*

One mother responded to her child's deafness by not listening to music anymore and connected this action to a state of being somber:

> *M: The first three years were the worst. I would not put music on at home anymore, I would not sing anymore ..Things were very somberly, like 'what he cannot enjoy, I cannot enjoy'. (C12ab)*

Yet, there is still more to be said about the concern over silence. Contingent or subtle sound - that is sound on that we do not perceive consciously - structures the world around us. As such sound may be said to be a part of our "natural subconscious décor": the singing of birds, passing cars, steps on the floor, the buzzing sound of a computer monitor, the whispering of the wind, the clattering of rain. If we return to the concern over music, music may also be perceived as a metaphor for this natural, self-evident and subconscious "synchronizing" which "connects" hearing peoples' worlds (Powell 1990). It thus may seem that the idea of deafness results in grief because of the breach in the "tuning" of parent and child.

> *F. You know, it is something that we want to give her, like. we enjoy music a great deal and we, certain sounds that we hear, give us a certain feeling inside. And that is something that we do not want her to miss somehow... (C6)*

Parents also derive various more concrete sub-problems from the lack of sound. Perhaps these sub-problems can be aggregated under the denominator "disrupted understanding": it is deduced that the lack of auditory input will reduce the child's understanding of the world around him or her. Parents perceived of their child as "isolated" as the result of the lack of sound.

> *M... when she would be playing in a corner of the room she would not look away unless a truck would pass by as it would cause the house to shake. That is when she would notice something happening. Or if the door would open or the light would be turned on. Besides this, she would notice nothing really. (C5a)*

The hearing disability is hence postulated to cheat crucial information from the child, which in turn would make apprehension of the world vastly more difficult.

The diagnosis as relief

A number of parents said to have experienced much less emotional staggering than one would perhaps expect based on the preceding, hence complicating the overall picture (Kampfe 1989; Beck 1996). Sometimes this was explained by the conviction that they [parents] were able to deal with the situation:

> *F: It did little to me. We had suspected it but, eh, I had full confidence - this may sound banal - that things would be all right. Confidence in ourselves as parent and in our son, like "Ok so he's deaf...so what?" (CO5b)*

Some parents confessed that the final diagnosis of deafness was experienced as a confirmation of their concerns (Beck 1996; Isarin 2002). The diagnosis connected what seemed like contingent events up to then. Two out of three parents who made such statements were the parent of a congenitally deaf child (C13, C14b).

> *F: That was the odd thing when we finally found out [that child was deaf - ccw]. Of course it was a major blow, but also a great relief. Everything just fell into place. For example, that she had such difficulty standing-up and walking. She has no sense of balance so it was quite logical that this was more difficult for her compared to other children. [.] All sorts of symptoms that you did register, or perhaps it is better to say observed, now fell into place. The puzzle was complete· of course, she is profoundly deaf! (C13)*

> *M: We were told [that the child was deaf] by the otolaryngologist. The otolaryngologist yes, and we took a deep breath. But at the same time I had a strong presentiment that she was deaf. I was certain about it. [...] I knew very certain that things were not all right. (CO6b)*

> *M: Yes, we were relieved because the past year was full of uncertainty, like "what is the matter with him". (C14b)*

One parent had worried about other more ominous diagnostic options; the exclusion thereof was experienced as a relief as well:

> *M: On the one hand it was a relief, because the diagnosis now proved that his brain was working well. It was terrible but also a relief to hear that he was not spastic...(C14b)*

In addition, for parents of a child with congenital deafness who experienced general pedagogical difficulty with their child such as those paraphrased above, the diagnosis provides a liberation from personal guilt and feeling of inadequacy over the events experienced, by displacing the motive beyond the realm of parents and child as individuals: it is not they (as failing parents) or the child (renouncing parental love) who were to blame for the relational and pedagogical problems, but rather a "neutral" agent, namely deafness.

Specific issues, cases and controls

It appeared that the diagnosis caused more emotional upset to some parents of congenitally deafened children as compared to parents of children deafened by meningitis (Becker 1976). The sense of gratefulness, having survived a life-threatening disease, may be one explanation.

> *I: What did you think when you were told that your child was deaf?*
> *M: I've got a deaf child, but at least I still have her. I know quite well that meningitis can do a lot of damage! (C1a)*

> *M: We were so glad that the function of her legs improved. Now we say, she is only deaf. If you would have seen how sick she was, yes, from that perspective she is only deaf (CO4b)*

> *F I always feel that way [...] sometimes you just do not realize that, damned, we could have found him dead in his crib you know? (C11)*

Interestingly one parent of a congenitally deaf parent exposed a similar view, yet her deaf son also suffered from life threatening heart disease:

> *M: I was not really interested in it [diagnosis], I was too busy with his heart. I could not care less about his hearing as long as he just survived. (C16)*

Another explanation has been suggested by Burton, arguing that acquired deafness is a more "acceptable" cause of deafness as compared to genetic deafness (Burton 1975; Philp 1982). If "genes" are responsible for deafness several semiotic aspects can be derived from this. Firstly, that apparently one's genes consist of the *potential* to cause a defect, which may transfer part of the defect to the parent him or herself. Secondly, if genes are the cause of deafness, this may constitute a sense of guilt. This would be

particularly true in the case of a second deaf child. Indeed we found that the upset caused by a second deaf child was even greater than in the case of the first child. In a cynical futuristic essay Sadée describes how children may sue their parents for genetic defects (Sadée 2001). That his view may not be all that preposterous is illustrated by an actual case:

> At a different level ... is a controversial case in France about a parent couple who gave birth to a severely disabled child. The boy sued his parents because they and their DNA are responsible for his misfortune. "I should never have been allowed to live", is in fact his accusation. (Sadée 2001 - translation ccw)

While none of our respondents underscored this suggestion verbatim, it was noticed that talking about the cause of deafness proceeded differently in the two groups. While parents of meningitis children commonly were preoccupied with how the illness could have been avoided, parents of congenitally deaf children were sometimes uneasy talking about etiology.

> *M No, we did eh...you know testing and such and, well, eh...they nevertheless hypothesized from a, eh...well sort of a genetic eh abnormality...(CO5b)*

> *I: Do you know how she became deaf?*
> *M: No, they don't know, they did not find anything.*
> *F: No, nothing, no...*
> *M: And then they said like, eh, it happens to 1 in 1000 babies. That they could not say what it was [...] They do not exclude a genetic cause you know? So it may be that, eh, a long long time ago there was someone in the family, or she may be the first, you know. We will never know (C2b)*

Two parent couples more or less rejected heredity diagnostics:

> *I: Born deaf, do you know the cause?*
> *M. No, we never sought diagnostics for this.*
> *I. Never sought diagnostics?*
> *F: No and we do not want that. (C8b)*

> *I: Did you consider genetic counseling after the birth of your child?*
> *M. Yes we did. But we thought, to what conclusions does it lead? That you do not want any more children? So we certainly did not want that. I wanted another one [...] All that diagnostic stuff...they simply are good children but they are deaf, period (CO7)*

One parent couple however did fully subject their deaf born child to genetic diagnostics, yet it did not yield a concrete diagnosis (C14b). However, this couple was advised by others *not* to seek a genetic answer:

M: We talked to people who also had a deaf child and they said: "No, you should not determine it genetically because, what does it matter? It just is the way it is. It does not matter if it is because of you or something else It is just the way it is. It's a fact." (C14b)

Other less tangible explanations explaining the lesser shock in acquired deafness may be: 1) the knowledge of the concrete possibility of deafness (that possibility had been medically confirmed while in congenital deafness it was not), 2) the relatively short delay in diagnosis, 3) the understanding of how and why the child is deaf (there is an understandable cause for deafness) and 4) the prolonged exposure to medical care casu quo the gradually growing awareness of deafness.

Conclusions

Summarizing this section, it was found that most parents experienced the actual moment of the diagnosis as a severe emotional blow. Burton for example reports that almost 90% of parents experience "feeling ill" or "depressed" around the time of diagnosis of disability (Burton 1975). It is mentioned however that these finding have not been reproduced consistently by other studies (Rutter 1970; Philp 1982). Quite often, parents used cataclysmic language to describe their experience. In general it appeared that parents responded rather congruent with coping theory (Kübler-Ross 1969). For example, parents had difficulty acknowledging the permanency of the condition. This was expressed by their hope for a diagnostic mistake, their quest for cures and the tendency to downplay the severity of deafness.

The character of the emotional upset appeared strikingly diffuse: most parents could not explain *why* they were struck by such intense emotions of terribleness. It hence seemed as if their suffering originated in "common sense", in the way we view disability in our culture (Isarin 2002; Philp 1982). Some more specific concerns were mentioned. Parents feared that deafness would preclude any form of happiness for their child. Parents feared that deafness would severely inhibit their child's communication skills, which in turn made them fear that it would prove impossible to form a meaningful relation with this child. Finally parents feared that institutionalization loomed around the corner. It was our impression that parents of congenitally deaf children suffered more profoundly as compared to parents of meningitis children. We suggested that this may be explained by the fact that the latter parents had experienced the life-threatening meningitis episode, which could have encouraged a sense of "appreciation" that their child was still alive. Alternatively we suggested that congenital deafness is a tougher diagnosis to bear because of the potential personal implications: if a defective "gene" is the cause of deafness, this may translate to those who passed on that gene: the parents. Indeed we found that parents of congenitally deaf children were hesitant to talk about the etiology of their child's deafness. Besides an intense sense of agony some parents were also struck by guilt. This appeared especially true for parents of meningitis children, as

they pondered if they could have prevented the events that caused their child to lose his or her hearing. The issue of silence appeared frequently in the interview material. It appeared that this issue symbolically expresses most of the concerns that we mentioned above.

In spite of the strain caused by the actual diagnosis, some parents told us that they experienced relief as well. This apparent paradox is explained by the clarity or sense of order that a diagnostic category inherently provides. As such parents of congenitally deaf children expressed it in particular. As we discussed in the previous section, these parents went through a prolonged period of uncertainty, a period during which they had a strong sense of "something being wrong" without being able to pin it down. This may have even caused some parents to question themselves, to question their role in the problems they encountered with their child. The final diagnosis nullifies these unpleasant uncertainties. As such, the medical diagnosis in general provides a safe haven by releasing the individual from personal accountability (Wever 1997). The relief experienced through a diagnosis has been described in other contexts as well (Isarin 2002). A similar response has been described in people who acquire a chronic slowly progressive disease such as multiple sclerosis. Wever and Oderwald for example, argue that the diagnosis is hybrid in its meaning for such patients (Wever 1997). On the one hand they embrace its structuring effect, marking the time in a "before" and "after" and paving the road to narrative cohesiveness so to say, yet at the same time they resent its specific pathetic social content as well as its implications of permanency and powerlessness - it is the "wrong" narrative so to say, the specific narratological cohesiveness is one they could do without (Wever 1997). A parallel may be drawn to other medical conditions with strong negative social connotations aimed at the individual itself, such as Chronic Fatigue Syndrome (CFS).

AFTER THE DIAGNOSIS

Introduction

In the previous section we elicited the direct response to the diagnosis. It was shown that at least initially parents had great difficulty in dealing with the fact that their child has a severe handicap. Yet it is unclear if this situation persists. In this section we will describe how parents dealt with their child's deafness in the immediate aftermath of the diagnosis.

Dealing with deafness

After time, most respondents were able to relativize the cataclysmic image of deafness, which seemed to sooth their agony (Beck 1996). This has been described in the context of other disabilities as well (Reinders 2000). It appears that parents experience that having a deaf child is not as terrible as they had initially thought. Initial fears of a fundamental lack of happiness were disproved by experience. The world parents envisioned initially is not the world they actually encountered and experienced.

> *F: A lot has changed. It had an enormous impact. It puts your life up side down but you learn that the world up-side-down looks rather different [than you thought] and rather new (C13)*

It appears that the child him or herself was *essential* in this respect (Scorgie 1996; Reinders 2000; Isarin 2002). Parents come to experience their child as rather happy and cheerful, thereby countering the gloomy perspective common to the initial response:

> *M: I was sad at first. On our way back from the audiological center I was crying in the car and then my husband said: "look, just look at that child. He is sitting there cheerful and all, smiling and happy. Sure it is sad that he is deaf but you don't have to be sad all your life! Just look at him!" (CO5b).*

> *F: He made it easy for us [accepting deafness]*
> *M: Yes, because he is so cheerful. (C14b)*

The same was true for the fear of an insurmountable communicative barrier:

> *F: After a few months we noticed that he started to pick it up [communication through Sign language] and that made us feel like "wow" [it is not that bad - ccw] (C14b)*

While grief did not subside, parents felt a need to control it. Parents appeared to perceive grief and distress as "conflicting" with the love they experienced towards their child.

Grief may be explained in terms of disappointment, which appears contradictory with the notion of "unconditional" acceptance or love, which is common to modern parenthood.

> *M: Sure we had our tears and worries, but that is not very supporting to your child now is it... (C2b)*

> *M: Acceptance is something difficult. Sometimes you are sad because of her deafness and she'll ask me why I am sad. How do you explain that? Yes, I find it troublesome that you are deaf and the things brought along by deafness? I feel I cannot go into that too much, it may affect her too much you know. (C15)*

> *M: You [speaks towards the father -- ccw] feel that I deny him if I say that, if I say that it [deafness] makes his life more difficult, you feel that I feel pity towards him and deny him the way he is.*
> *F: I tend to postpone my immediate response because I am afraid it will hurt him. [...] I would fear that I would hurt him, if I would think like 'how pitiful he is' without knowing where he is heading really (CO5b)*

Parents feared that their child would come to experience a sense of "inadequacy" from enduring parental suffering, something that they wanted to prevent. Indeed Paul states that a deaf child will likely read distress from a mother's face, which may lead him or her to withdrawal (Paul 1993).

Similarly to what Isarin has described, rather than dwelling on the gloomy uncertainties of the future parents seemed to refocus their perspective on a "smaller world" and on a shorter time-axis, thereby visualizing and highlighting the rather positive actual situation and progress the child makes in these terms while "shoving aside" the future, which likely contains critical worries and uncertainties (Isarin 2002).

> *M: The long-term planning has been condensed considerably. (C13)*

Parents tend to focus on what *can* be achieved rather than on the things that cannot. As Isarin states:

> In a small world large goals become relative. [...] In a small world history and future meet in the today that demands an answer to the question if one can live with the situation today. In this world there are no acts of heroism, but one lives with the facts on a day to day basis. (Isarin 2002 – translation ccw)

This change in perspective may go hand-in-hand with a change in expectations. By parting from the road of expectations of a normal child, a rather unique or personalized perspective arises.

> *M: We have several children with disabilities in our neighborhood, so you start to look at it differently; you look at what he can do (C14b)*

Specific issues, cases and controls

We found no discerning evidence that cases responded differently compared to controls in this context. Both seemed to reconfigure themselves rather swiftly after the diagnosis was established.

Conclusions

The cataclysmic experience that we described in the previous section did not appear to persist for long. Indeed Beck notes that some parents experience rather little agony or succeed to resolve these emotions in a matter of weeks (Beck 1996). It seemed that direct experience with their deaf child was essential in this context. Parents soon experienced that their child was doing rather well in socio-emotional terms, thereby dismissing the negative expectations they held before. As communication evolved, the fear of an insurmountable relational barrier also vaporized. Finally parents started to focus on a "smaller world" set in the present mainly. The future, with all its uncertainties and gloomy scenario's was shoved aside. Still, grief persisted which may explain that we found evidence for an ambiguous attitude in some parents. Parents felt however that they actively needed to control this since it conflicted with their desire to love their child unconditionally and feared that their child could sense it.

DISCUSSION

One could suggest that if one is to find the most "uninhibited" response to "deafness", it is likely to be in the period under scrutiny in this chapter. It has been suggested that this uninhibited response of parents - MacKeith speaks of "biological" response (MacKeith 1973) - may provide important clues on how parents decide for their child, both short term and long term. The earliest response to deafness seems to be connoted to "authenticity" in terms of the psychological and attitudinal roots of parents and as such is hypothesized to modulate the decision making process. In this chapter we described parents' experiences prior and directly around the diagnosis of deafness. One of our most central conclusions was that parents were shaken intensely by the diagnosis while they were unable to explain why this was the case. It seems reasonable to assume that what parents' experienced is rooted in collective scripts on disability. Though parents had little specific knowledge of deafness, as members of society they are likely to share the collective scripts vis-à-vis handicap. The actual moment of diagnosis may therefore be argued to reveal information on our collective scripts on disability, deafness and parenthood and may evoke a collective or "generic" experience (Philp 1982). Indeed it was found that most parents described an experience that was very much similar. The content of the initial agony was diffuse, ergo contained little detailed description of what it means to be deaf besides that it must be "terrible". It is exactly this superficial and prejudice view on disability in general and deafness in particular, sometimes labeled as the "medical perspective" that disability organizations have depicted. It seems likely that, given the state that we have described, if parents have to decide for their youngster in this stage, that such decisions will a priori be pitched strongly towards eliminating deafness. We have also shown however that parents soon succeed to reset themselves and that experience with their deaf child was central for this to occur. Parents achieved this in part through experiencing the invalidity of some of their initial fears, but they also did by actively subduing their grief and fears and "shoving aside" the future of their child. This may explain why we found some parents to describe their experience as ambiguous as it appears unlikely that they will be successful at subduing their fears and shove aside the future at all times. It is as such unclear if this change of perspective is sufficient to refute the aforementioned tendency to eliminate deafness a priori. In the next two chapters we will continue to explore this issue as we will survey how parents faced deafness on the longer run, describe the decisions they made and try to probe for possible associations between the two.

INTRODUCTION

Introduction

In the previous chapter we described how the emotional upset that parents experienced around the time of diagnosis was profound in intensity yet surprisingly global in content: parents narrated of having experienced profound sorrow but were generally unable to provide a detailed decor for this sorrow. What dominated parents experience in the earliest days was a diffuse and non-specific sense of tragedy, which we linked to the dominant prejudiced view on handicap in our society. Only if this situation persists however, which some have argued (Hindley 1993; Meadow 1987; Schlesinger 1988), it appears plausible that the decisions parents take for their deaf child will be at least in part the product of this gloomy perspective or "intuition" rather than being born out of a "critical" appraisal of their child's best-interest primarily (Hare 1989). Indeed it may be argued that such intuitions are limited in scope and in fit to reality, and as such are questionable in their suitability to base decisions on, consequently casting doubt over the moral justification of decisions that follow from them (Hare 1989).

Yet it is far from certain if the panorama that we described is enduring and if parents actually base their decisions on these early prejudiced intuitions. After all, the previous chapter provided some evidence of change. Parents soon succeeded to "reset" themselves in the sense that they actively suppressed their prejudiced intuitions and also experienced that some its ingredients were rather unfit to reality. Yet we also argued that it is uncertain if these changes are enough to silence the initial emotions sufficiently. It may very well be however that the process that parents initiated in the previous chapter continues to develop as time goes on. Parents are likely to grow both in terms of their knowledge about deafness as well as their hands-on experience with their deaf child. One could therefore reason that a second narrative may establish itself as time goes on: a narrative that is constructed through hands-on experience and factual as well as experience-based knowledge. This narrative is not necessarily congruent with the initial agony that was experienced around the diagnosis and as such can potentially modify or "transform" parents' experience (Isarin 2002). Indeed, Clare and others found that early parental views regarding their handicapped child had low predictability vis-à-vis the decisions they eventually made (Clare 1998; Broesterhuizen 1992). Rather it is reported that experience with the child is a determining factor (Clare 1998; Mahoney 1958; Scheuman 1963). Broesterhuizen also advocates distinguishing the "early response" from the "more enduring attitude" that may arise later in time (Broesterhuizen 1992). Isarin comes to a similar conclusion in her discussion of the wisdom of the "self-willed" mother that evolves after time (Isarin 2002). Isarin chooses to speak of "wisdom" to emphasize that such parents draw from more than scientific knowledge alone.

> In daily life parents gain knowledge through experience with their child, the environment and the experts; professional knowledge is selected, interpreted and applied; own insights become interwoven with borrowed or appropriated insights. In other words, a wisdom is acquired that is one's own, though she is not independent of medical knowledge. (Isarin 2002 - translation ccw)

Still, it would be wrong to ignore the possibility that some parents continue to experience profound strain, so severe even that it inhibits their ability to make calculated decisions (Belsky 1984; Dekovic 1996). Indeed it has been argued that some parents are unable to break through the dominant gloomy social narrative on deafness, which could result in persistent grievance and, again, the perpetuating inclination to "eliminate deafness" (Kampfe 1989). If this thesis has validity, it is most likely to manifest itself shortly after the diagnosis is established and as such is most likely to impact the decisions that coincide with this early period, most importantly language and school decisions. Indeed, if one summarizes the literature about parents of disabled children in general, this seems to be a prevalent working hypothesis: it is assumed that the earliest parental experiences and responses are related to later decisions in some way or another (Vernon 1984; Hoff-Ginsberger 1995; Schaefer 1991; Krietler 1976: Bruce 1994). Thus, the implication of many studies has been that early parental responses provide insight into how parents decide for their child later in life - a certain power to extrapolate or stability over time is apparently assumed.

Deaf literature has also been moderate to strongly opinionated about what parents of deaf children experience, what "attitudes" they exhibit and most importantly, how these factors drive their decision making, both in short- and long-term. Several specific suggestions have been made, particularly about parents who choose for an oral environment. It has been argued for example that hearing parents "expected" a healthy and thus hearing child when they chose to have children, which would predispose them towards decisions that are primarily aimed to "correct" the dissonance that a deaf child represents (Hadadian 1991; Cowen 1967). Indeed it seems likely that parents hold "silent" or implicit expectations of their progeny, a "blueprint" in terms of Larson, expectations such as those regarding health and general school career (Larson 1998). Isarin states that mothers *at least* hope that their child will be healthy, has "ten toes and ten fingers" so to say (Isarin 2002). One could argue that some of these expectations are congruous with "general pedagogical expectations". Clark-Steward found that almost all American parents read at least one parent-manual and quite a few read more than five of such volumes (Clark-Steward 1978; Hays 1996). In addition, parenting and women's magazines actively contribute to the shaping of expectations (Eyer 1996). However, the relation between these texts and parents expectations should not be perceived too much as a one-way street. As Hays has argued, "the popularity of these particular manuals, rather than others, indicates that they have struck a chord with readers" (Hays 1996). Marschall, Eyer and others have argued that these volumes have an important social function (Marschall 1991). Nevertheless, most expectations are likely to be implicit,

vague and global (Steutel 1992). On the other hand, Simons states that in the case of disability these implicit expectations are likely to become explicit:

> As soon as a woman becomes pregnant, both parents begin to fantasize about the child they will have. The child will be perfect - beautiful, successful, all the things the parents would like to be themselves. Sometimes they talk about these dreams together. Sometimes they don't even realize they have them...until their child is born. Then suddenly they hit. In the case of a child with a disability, parents spend much of the child's early life learning to accept that the child they have is not the child they wanted. (Simons 1987, 5)

Finally, the concept of "attitude" arises in analysis of how parents reach decisions. Theoretically, an attitude is "a disposition towards a specific behavior in light of a specific object" (Scroggs 1988). Otherwise phrased, it is a stable tendency to respond in a *specific* way towards an object. Like character, attitude is often perceived as a "trait globality": it is often assumed to be stable across a wide range of situations or contexts even though some have cast serious doubt on this presumption (Musschenga 1998; Flanagan 1996; Fromm 1994; Witlox 1996). The concept of attitude may be perceived as a "modifier" of both expectations and emotional response and as such has been described as a strong factor of influence on how people act (Scroggs 1988; Cattell 1952). If certain expectations or emotions such as grievance become "consolidated" and insensitive to context, one may consider them to be much like an attitude. All parents will gain experience with their handicapped child and most will also leap forward in terms of knowledge. The different decisions parents make must thus be explained by intrinsic factors or "traits" that modify how these experiences and knowledge are processed, so it seems to be assumed. Attitude may be said to be such an intrinsic factor (Scroggs 1988).

In this chapter we will explore the viability of both hypotheses. As such we will focus on how the parental panorama develops in time and describe the actual language and school placement decisions taken. Before we turn to our empirical material however, it is necessary to define our concepts more specifically. We will do so in the next paragraph. Next we will turn to our empirical material so gauge parents' attitudes towards deafness. Finally we will discuss the concrete decisions parents made regarding preferred language and educational placement and see to what extent these decisions can be related to their views or attitudes towards deafness.

Extracting operational terms

As we argued in the introduction of this section, the thesis that parents decide based on early and (prejudiced) intuitions primarily certainly has theoretical merits. Yet to assess this thesis in an empirical setting is rather complex. First and foremost one will have to establish if parents indeed exhibited specific, coherent and consistent emotions or

intuitions that we can speak of an "attitude". Next one will have to evaluate if such an attitude is enduring and moreover, if it can be related to the specific decisions taken.

Perhaps the biggest problem in realizing this is the difficulty of probing for attitude empirically. Though some have attempted to do so, the concept of attitude refers to a fairly abstract state and as such is difficult to "measure" (Philp 1982). Yet there is another complicating factor which potentially undermines the operationalization of the concept in an interview setting, which is related to the moral connotations it often bears and which will make it a likely subject of narrative transformation: if for example parents do or did feel "disappointed" about their child or are experiencing difficulty "accepting" their child's deviance, they may be unlikely to disclose this because this is socially undesirable. Alternatively one can pose the question which tangible derivatives, which should preferably be less morally charged and less cognitive in nature, can be extrapolated from the theoretical concept. Philp suggests that one can think of 1) convictions, 2) less abstract emotions and 3) "behavioral reciprocals" (Philp 1982). We will discuss these briefly.

In light of what we discussed it would be interesting to probe for specific convictions that could have implications for how parents decide for their child. One could perhaps expect that parents have specific (negative) convictions regarding the alternative of Sign language and Deaf culture. Perhaps they find Sign language an inferior language, perhaps they view Deaf culture as limiting and perhaps they renounce the self-chosen isolation of Deaf culture. One could perhaps also expect that parents view spoken language as too demanding or limiting in terms of psychosocial development. Another possibility is that parents feel that an oral environment cheats the deaf child from his or her identity. All of these suggestions can be encountered in literature. Yet not all of these convictions appear to fit the description of a "basic outlook" that one would expect of an attitude. A basic outlook is defined as an outlook which does not require specific and complex knowledge nor experience, an intuitive or "ignorant" outlook perhaps which parents more or less share with non-experienced people who have had a minimum introduction into the world of deafness. The most logical "conviction" that we would expect in this context is the conviction covered by the social narrative on deafness, namely the conviction that deafness is a terrible event that must lead to a dreadful life.

If parents hold the conviction that deafness is a terrible condition as described above, one could expect specific emotions to arise along with this. In this context, one could perhaps expect the appearance of emotions that represent a specific casu quo negative view towards deafness, such as pity, sorrow and shame. Pity and sorrow may be argued to reveal the persistence and intrusiveness of the dominant social narrative on deafness.

> A child with attributes that are experienced as alien, unwanted, unbearable or incomprehensible is always at the same time a unique self. As such the attributes of the child are transferred to the self: as failure, guilt, incapacity. (Isarin 2002 – translation ccw)

Shame is another emotional state that we should consider. Lazarus categorizes shame under the denominator of existential emotions because "the threats on which they are based have to do with meanings and ideas about who we are, our place in the world, life and death and the quality of our existence" (Lazarus 1994). Shame can thus be said to be situated in the relation individual-environment. As Giddens points out, shame is highly related to the Other by being an expression of social acceptability (Giddens 1991; Bauman 1991). In Lazarus' view shame represents "our failure to live up to our own and others ideals" (Lazarus 1994). Though it may often be the case, the Other needs not be a physical other since shame assumes internalized standards (Lazarus 1994). Shame over someone else is a somewhat odd construct from this perspective. How can one be overtaken by emotions of shame if the subject is not the Self, as is the case in parenting? Shame through "displacement" is one possibility. The displacement establishes a link between the subject of shame and the Self through identification: it could have been me who experienced the event leading to shame. However, the child-parent relationship is different from the relation between two unrelated individuals. One could suggest that some degree of identification between parent and child is established naturally as the parent conceives of his or her child as a part of the Self (Jacobs 1993b). Gresnight states that parents may experience their child as a physical and psychological extension of the Self (Gresnight 1973). This could cause parents to feel that having a disabled child somehow "rubs off" on them, hence inducing shame. Goffman has suggested that the discomfort parents experience in encountering others may be the result of partial inclusion of the parent him or herself into the social stigma of disability, a phenomenon Birenbaum labels as "courtesy stigma" (Goffman 1963; Birenbaum 1970):

> A second type of wise person is the individual who is related through the social structure to a stigmatized individual - a relationship that leads the wider society to treat both individuals in some respect as one...the parent of the cripple...(is) obliged to share some of the discredit of the stigmatized person to whom they are related (Goffman 1963)

The latter option seems particularly conceivable in parents of congenitally deaf children, since genetics provides a direct link between parent and child. As Paul and Jackson state, parents may ask themselves what they "did wrong or did not do to ensure a healthy, intact baby" (Paul 1993; Birenbaum 1970). Waterman for example, quotes one mother of a mentally disabled child as saying: "I have created something defective, I am a failure" (Gresnight 1973; van den Boer 1997).

Taking into consideration the negative connotation of the convictions and emotions that we discussed, it would seem unwise to navigate on the prevalence of them alone (Gresnight 1973). As an alternative one can probe for behavior reciprocals. The thesis that parents sometimes "reject" their disabled child is upheld by some (Philp 1982).

Intrusive pitiable emotions are likely to induce an inability to experience and express authentic love towards a child (Isarin 2002). If parents would continue to hold a strong negative image of deafness, this could interfere with the development of an emotional bond that is "authentic" in the sense of being averse to intrusive pitiable emotions instead (Gresnight 1973; Schaefer 1959; Bruce 1996; Isarin 2002). Intrusively and perpetually experienced images or ideas regarding the disability of the child are perceived by some as a measure for ongoing grief (Bruce 1996). As we have explained in the introduction of this chapter, if parents persist in holding a strongly negative image of deafness and are unable to imagine that a deaf individual can ever be happy and live a fulfilling life, this gloomy perspective may come to dominate the parent-child relationship in such a way that parents cannot think about the child, be with the child, care for the child independent of this thought. One could hypothesize that if emotions of pity strongly dominate parents' emotional relation with their child, they may engulf parental love and commitment and as such may obstruct the development of a satisfactory and authentic parent-child bond (Paul 1993; Philp 1982).

> It is the persistent and unrelieved holding of unrealistic negative values of the child to the extent that the whole behavior of the parents towards that child is colored unrealistically by this negative tone. (Gresnight 1973 – translation ccw)

Another potential indirect gauge may be socially "evading behavior", behavior in which the encounter with others is avoided to thereby diminish the opportunity for painful confrontations. Such behavior has also been interpreted as symptomatic of ongoing grief (Bruce 1996). Avoidance behavior has for example been described in parents of children with a mental disability (Bruce 1996; Bruce 1994).

In the above we have provided some possible operators, extrapolated from the general representation of parents of disabled children in literature. It is emphasized that these operators are not intended to be encompassing.

Guidelines for an inquiry into attitude

- Cognitive convictions
    - Expectations
    - Convictions about the state of being deaf
- Emotions
    - Disappointment, resentment and shame
    - Pity and sorrow
- Behavioral reciprocals
    - Rejection and evading behavior
    - Inability to form an authentic relationship

This framework will be an orientation point for our inquiry, particularly in this chapter. As stated, we will focus on the global image. More detailed or specific convictions and ideologies that reach further than general views on deafness are deferred to later chapters.

It is emphasized here that we are not so much interested in these emotional states in their "incidental" appearance but rather in their structural figure. It is hypothesized that only structural emotional states are likely to have a significant influence on these processes. Incidental shame or pity is considered "normal" in most relationships and of little influence.

EXPECTATIONS AND ITS POTENTIAL CORRELATES

Expectations

Few parents explicitly spoke about the expectations they held before deafness came into play. One parent emphasized that expectations are rather abstract concepts when dealing with very young infants:

> *M: He was nine months old, there is just not a lot you can say about that really. It is just not an issue. (CO5b)*

As we argued however, if a child is disabled implicit expectations are likely to become explicit as well as the need to modify them: surely people do not expect to get a child with a disability (Steutel 1992). One parent explained that the initial ideal image was at least that of a hearing child:

> *M: The Philippines story was a primary response, like she cannot be deaf. She must hear, that kind of perfect image. (CO7)*

Beyond deafness and hearing, parents drew a very global picture indeed. Parents recognized that the "normal career" in terms of major landmarks would not a priori apply to their child in the future. Parents seemed to accept the relative uselessness of "normal" expectations, but beyond that they were not really occupied with the future.

> *F: The future perspectives are different, that is the biggest difference (C13)*

> *F: It is wiped from the table instantly, that you just have to wait and see how things work out in the future. (C9a)*

> *F: I think you have that flexibility. If you have certain expectations, and every parent does, you need to modify them. (C4ab)*

As we described in the previous chapter, parents did not appear to dwell on the future and as such did not appear to hold an "encompassing" view on what they ought to expect from their child in the future. Rather they focused on and responded to the problems encountered in day-to-day life. Clearly the "unfitness" of the normal career materializes in the present as well, be it in "smaller steps". This implies a need for resourcefulness in everyday life. It appeared that parents were generally aware of the need for resourcefulness and were able to provide in this respect.

> *F This is not a normal child for whom you have unconsciously stipulated a certain path, just going to school, to friends and such. Suddenly you have to make an effort. Arrange this, organize that. That is the biggest difference (C13)*

It appeared that parents were not concerned with the "larger scheme" at this point but were much more pre-occupied with the immediate and with affective-relational values. The future and its unmistakable problems seemed to be ignored or "shoved-aside". Expectations were commonly unrelated to physical normalcy or distant social career landmarks but rather strikingly affective-relational in origin: as we discussed in chapter three, this concern stems from parents desire to establish communication and a healthy parent-child relationship. (West 1998). The societal futures that *were* envisioned were rather skewed towards socio-emotional functioning or "being expressive" in some way or another.

M. I just want him to be happy (C12ab)

I Is that important to you in your deliberations, how your children are doing socially?
M: Yes sure, socially and also that they are self-confident. That they have self-knowledge, know who they are. And that they feel OK, yes. (CO5b)

I: If you think about the future, what is your perspective?
M. She is creative but well, she does not know what she wants. I picture her working in a flower shop or something, where she can express her creativity (C2b)

M: Well, about work. I think it would be nice if another deaf person would join her at work. At least you can make contact during the breaks. You know, have contact (C6)

Even if parents were asked explicitly about their future expectations, their answers continued to focus on such affective-relational issues.

M: He [deaf child] has made plans as well. He'll be working close to his father, in the neighborhood of his father. His father will take him with him in his car. During the lunch break the two of them can have a meal together, nice and cozy, and have a chat. (CO5b)

I: If the two of you consider her future, what image comes to mind?
M. Well I hope. I do not really know. I hope she gets a good job and that she feels comfortable in it And, ah, like my son, a pleasant family and a pleasant life. (C15)

M: No It just does not matter to me Even if he becomes a carpenter, just leave him. As long as he feels good about himself, as long as he is alright, has self-confidence, has social relations, it is fine with me. (CO5b)

I: What would be a future with which you would be satisfied?
M: For the future? That is hard to say, as long as he is happy it does not matter to me where he ends up. As long as he enjoys it, he does not have to become a CEO, as long as he does what he wants. If he wants to do manual labor or whatever, it does not matter to me, as long as he enjoys it, it is good enough for me. (C8b)

Even though parents generally refute that they held expectations beyond the affective-relational realm, many said that this issue did arise early on in their contact with counselors. Apparently counselors assumed that parents held specific expectations and discussed this with them. A few parents spoke of the explicit call of counselors to "adjust expectations" as soon as the diagnosis was established.

> *F: We were told that our infant was deaf However, the shock over the diagnosis was overshadowed by the subsequent comment that we could better adjust our expectations of this child radically and rapidly. First of all, we did not have many expectations of our child· it is our philosophy that we follow each child in his or her development. The suggestion that we did hold expectations was insulting. Secondly, for those expectations which we did hold, we did not see why these needed to be altered only because of deafness. (CO5b)*

Counselors discouraged parents to hold expectations in terms of "normal" career landmarks. Instead they seemed to promote rather "modest" expectations, as we will address extensively in chapter 5. Indeed it appeared that most parents responded "well" to the call to temper expectations. Some parents did more than "shoving-aside" the future and adopted the rather modest expectations advertised by counselors.

> *M: We never expected that he would ever attend regular grade school...(C5a)*

> *F. He still has two more years to go before making a decision. He does everything. He makes birdhouses, paint, woodwork, ironwork, bake, cook. (C3b)*

Hence, those parents that *did* present concrete future expectations often expected little and valued social-emotional issues mostly.

Disappointment and resentment

Failure of a child to live up to parental expectations may yield feelings of disappointment. Certainly one needs to find new pathways for a disabled child as the paved routes do not apply, even though we illustrated in the previous section how these pathways concern an adequate response to pragmatic issues mostly rather than being in the realm "restoring" of expectations. This seems to weaken the likelihood of disappointment (Philp 1982). Indeed we did not find utterances that revealed disappointment.

Yet the fact that deafness requires parents to be inventive in order to respond adequately to the problems induced by deafness may cause resentment. Philp for example mentions categories such as "inadequate housing", "lack of mobility", "aids", "transport problems", "impact on leisure time", "employment" and "financial burden" as pragmatic issues that need to be addressed. Indeed Simons claims that "all parents feel angry at

their handicapped children for the tremendous disruption they inject into their lives" (Simons 1987).

> All I wanted was a baby and now I've got doctors' appointments, therapy appointments, surgeries, medical bills, a strained marriage, no more free time (Simons 1987, 15)

Having a child in itself yields considerable changes in the life of parents, changes that may not always be welcomed In most scenario's the introduction of a child in an established relationship not only implies changes in the structure of life, but may also effect the content of that life - particularly the parental relation - itself. Having a deaf child clearly implies an even more drastic change in the life of parents Some families for example, relocated across the country to be nearer to the deaf school of their preference. Having a deaf child thus implies facing time consuming problems that demand vast alternations in the organization of parents' personal life and family structure.

Indeed a few parents did express some general reserve about what had happened to them

> *M You can't just say 'close the door after I leave' when she is playing Or something like that You always have to walk over and tab her on the shoulder or get her attention in some way Everything you do is very much conscious, you can't communicate thoughtlessly You have to be on top of it, repeating things ten times 'cause she will fail to understand if you don't It is very exhausting at times (CO2)*
>
> *M You really need more time than you do with other children It is like having two children really (C1a)*
>
> *F Sometimes our family would visit for a day and by the evening we could "mop ' them from the floor! They were completely exhausted! (CO4b)*
>
> *M It is a hassle sometimes If we are visiting somewhere, we always have to get up and move towards him [to get child's attention-ccw] [ ]*
> *F It used to be a true disaster We could not go anywhere, we always had to keep him close by, keep watching what he was doing (C8b)*

Notwithstanding, none of our respondents seemed to experience these changes excessively negative and none held their deaf child "accountable"

Shame and evading behavior

As discussed in the introduction of this chapter, parents who hold strong expectations of normalcy, view deafness in terms of "defectiveness" and in addition are unable to revise these expectations and views, may experience feelings of shame towards their child. Even though shame does not necessarily require the physical presence of others since it

assumes internalized standards, the presence of others will likely provoke it or "revive" the prejudiced image of defectiveness that parents suppress. As a result parents may attempt to conceal deafness or avoid confrontation with others (Darling 1983; Goffman 1963). Contrary to children with a physical disability or children with for example Down syndrome, parents of a deaf child *can* "hide" their child's deviance rather effectively by not using Sign: Sign language and hearing aids are the only visible stigma of deafness. Though we did not probe for shame directly, so to avoid suggestion as well as to maintain a climate of confidence, we were watchful in exploring situations that could reveal its presence. Most importantly we were interested to know how parents felt about using Sign language in public.

It appeared that the use of Sign language in public was an issue for many parents. Yet the context in which these experiences were verbalized did not allow us to simply conclude that we were dealing with shame. Rather, the avoidance of Sign language in public may depict several distinct alternative experiences: 1) embarrassment over Sign language itself, 2) the desire to protect the child from the negative gazes that Sign language provokes and 3) resistance against "courtesy stigma".

It may be that "embarrassment" rather than shame is at stake, the object of embarrassment being Sign language in itself as a "funny" or "childlike" language.

> *M: Some parents just refuse to sign with their child in public They find it an embarrassing language, a 'monkey language' even. They will discourage the child to sign in public... (CO5b)*

Though shame and embarrassment may not be fully separable, embarrassment in general seems more transient in nature, less existential and located more in the reign of everyday social codes as compared to shame.

> Em.bar.rass v. 1. To cause to feel ill at ease
> Shame n. 1. A painful emotion caused by a strong sense of guilt, embarrassment, unworthiness, or disgrace
>
> The American Heritage Dictionary

Contrary to embarrassment, shame *does* seem to be an existential concept in the sense that shame does reveal how someone feels about him or herself rather than about a specific act. The caricature of the Dutchman is that of a somewhat phlegmatic or subdued personality (Heerikhuizen 1980). Against this cultural backdrop it may well be understood that some people experience embarrassment if they suddenly are expected to engage in a highly expressive body language, which Sign language is. A number of parents supported this hypothesis, casu quo attested that they had felt ill at ease using Sign language and explained this in terms of the physicality of that language.

M: If you look at it, I think that first and foremost one would find it highly exaggerated what they do. It looks outrageous, perhaps that is the first impression. [...] If you say "I like this" or "I like this a lot" or "I like this very, very much" you normally use your voice, intonation in your voice If you do it in sign, you have to express it through your face and body. [...] We felt a little ill at ease to do (C13)

M: They [the deaf] are much more physical [...] It's a much more primary language compared to spoken language. Of course I grew up with spoken language and we were not that tactile, rather the opposite. I realized that when I started making contact with her [in sign] (CO7)

M: He [husband] did not like it [Sign language]. He thought it was not esthetic
I. Sign language?
M: Yes, he did not like it. My husband is rather inhibited so he had difficulty with it. (CO3)

One mother mentioned that she did not have much difficulty in using Sign since she came from a very physical family:

M. we touch each other a lot . I guess you could say that we have southern features .. (C12ab).

Manual gestures may even be negatively associated with "aggression". Interestingly, the relation between the physicality of Sign language and aggression was mentioned by some parents, always in the context of play with hearing peers:

F. Yes, well they communicate different with each other, bumping and pushing...you know, just to get someone's attention, they pull or push...that is a bad mix with hearing people... (C8b)

M: If he wants to tell you something he will tap you on the back So his classmates, you can't touch each other right, would be working on some project...they would smack him. In turn this made him furious, thinking "I just want to tell you something", and he would smack them back. (C12ab)

It may also be that parents feel at unease using Sign in public not because it inflicts shame but rather for more pragmatic reasons: since it provokes stigmatizing stares, which in turn can make their child feel unusual, a side-show attraction even.

F: We have the same experience when we are at the supermarket signing with him; you are looked at then too. I can see them stare. I notice that. [...] I would much rather have them come over and ask like "what does he have" instead of gaping at him. We even experienced people gaping at him right in front of us. Just keep walking if you have nothing to ask! It is annoying.
M: I do not want that because I am nót ashamed of him, but still it makes me feel uncomfortable. Not because I am ashamed, but just because of those people staring for the reason that he is doing something out of the ordinary. And indeed, you may say that it is

not the case but it is It is like people in a wheel chair you may say that it is not different, but it is (C14b)

M Look, if someone is in a wheelchair everyone can see that he is handicapped And by using sign you show that your child is handicapped (CO3)

By avoiding Sign language in public, parents may be expressing their desire to avoid their child to be exposed to stigma Annoyance over the stigmatizing gazes of others can be encountered in numerous autobiographies of people with a visible disability (Wever 1997) In the eyes of bystanders parents encountered a "gaze" or "stare" which represents the prejudiced view on handicap, which reduced their child to an object, a "girl with hearing aids", a pitiable little girl

M I was hesitant to go out with my child [wearing her hearing aids- ccw], because people would start to look at her differently [ ] People would start to ask questions, which would make me feel as if she was not my own anymore but rather something different a little girl with hearing aids (C16b)

M It was just hard for me to go out with him They wanted to give him hearing aids early on
F We held it off
I Why?
M I did not want that
I Why?
M Because people will start asking questions and that makes me feel like, ' what do I have in the buggy, a pair of hearing aids? [ ] People look differently you know, they look differently than if it makes me feel as if it is not my child anymore they see a different child (C8b)

This prejudiced gaze conflicts with parents' apparent outlook on their child (Gresnight 1973, Weingold 1953, Darling 1983) After all these parents expressed that their child meant considerably more to them than what is encapsulated in the prejudiced view on deafness Yet based on what we discussed in chapter three one could also hypothesize that confrontation with the defective view on deafness threatens to "revive" the phantoms that parents just succeeded to suppress

What also seemed to trouble some parents is that identification of their child as "a deaf child" did not only stigmatize the child but parents just as much It appears that through "courtesy stigma" parents are excluded from the "normal discourse", just like their children are robbed from individuality through stigma They are structurally approached differently As soon as one starts to sign one is subject to the same stigmatizing gaze to the ignorant other one becomes deaf by signing just as much as one becomes physically disabled in the eyes of the naive passer-by by taking seat in a wheel chair (Birenbaum 1970) Yet the resistance does not exclusively originate from "rubbing-off" of part of the child's "imperfectness" or "defectiveness" on parents, but rather from the fact that

courtesy stigma limits parents conversational range to the "rules" set by this stigma, which robs them of their individuality. This is an experience that parents share with parents of children with disabilities in general (Philp 1982; Simons 1987) It is also similar to the experience of adults with a disability autobiographical work by handicapped adults clearly shows that "normal" present themselves in a rather prejudiced manner from which it is hard if not impossible to escape (Wever 1997; Spaink 1991, Spaink 1993).

> Strangers present themselves with an 'empathetic voice', 'large eyes of compassion' or 'excessive friendliness' (Wever 1997-translation ccw)

The next excerpts illustrate this latter suggestion:

> *M From the moment that I knew it [deafness - ccw] I could not call my friends immediately I just could not, because I thought the moment I tell them I become different As long as nobody knows it, I am just "Jane with two sons", no questions asked When you tell people, you become different because people will start to talk differently to you, you know? They will start to take your emotions into consideration because they don't want to treat you differently, yet it is different (C14b)*
>
> *M Just look at how things go in a restaurant If parents sign with their child there, people will instantly think God how pitiful They'll be staring at you (CO3)*
>
> *M If you sit in a wheelchair, wear glasses or hearing aids, for the average Dutchman you become handicapped really fast*
> *F The outside world will look at him like, what a pitiable boy Just look at what he is wearing [hearing aids-ccw] (C14b)*

It seems that this pitiable gaze is by no means restricted to the anonymous other, but affects intimates as well. Congruent with the literature on the matter, many parents acknowledged that they encountered this attitude in their interaction with family and close friends just as well (Darling 1983) Parents expressed difficulty in bridging the experiential gap.

> *I Did the diagnosis cause much grief?*
> *M At times, yes But more so the lack of understanding by other people For people who have never experienced anything, a child becoming ill, it is difficult to understand I think (C1a)*

Yet the possibility of shame remains and it seems rather difficult to distinguish it from the other explanations discussed above. Sign language *could* function as a proxy for or the focal point of the child's deviance, which parents may resent. If the above were true, one would perhaps expect more than the avoidance of Sign language is public. Perhaps one would expect outspokenly negative views on Sign language itself. Contempt for Sign language could as such be a "legitimate" proxy for the resentment experienced towards

the deviance of a deaf child. Indeed some degree of "contempt" for Sign language was encountered in almost all interviews. One sign of contempt arguably is the diminutives used by a few parents (CO7) to describe sign.

> *F: They communicate in their own way, 'cause it is a separate little language...(CO5b)*

Yet one could suggest that it is not so much contempt for the language in itself that drives these parents to use diminutives, but rather specific attributes of that language. Diminutives regarding Sign language appeared for example to be an expression of the tenderness which parents experience when signing during the early childhood years, not unlike the diminutives that parents often use in their spoken communication with small children. "Little language" may also be synonymous with the "little world" signing Deaf people live in. This latter was encountered frequently.

> *M: Because eh, if she cannot speak and just signs.... It is a very small world...*
> *F: Well Sign language, that little Deaf world. They may understand each other but if they visit the shop next door...Sign will be of little help (C2b)*

> *M: If you look at the statistics what is it really? It is a tiny little piece...(C7a)*

> *M: There is a deaf adolescent in our neighborhood and he would visit us on occasion. But if you see him now, he will be all-alone at the public pool, riding alone on his bike. That is not the image I have of her I find them a little pitiful really. Their world is so small I am sure one can have fun in a small group of deaf adolescents. But it is all so small and limited. (C10ab)*

> *M: Well, you see of course how most deaf adults...you really feel like 'I hope that does not happen to her' You hope that she will be able to develop herself better, can fulfill herself...(C15)*

Another example is that some parents considered Sign language as an instrumental language to establish early parent-child communication rather than a genuine alternative to spoken language.

> *M: We talked about it [Sign language] and received information about courses and such, but we did not have the need [since the child was proceeding well in spoken language - ccw]. [If she would not have been successful in spoken language - ccw] we would have missed contact with her, I think in such circumstance I would have for sure, everyone would learn Sign language then, because you want to have contact with your child. (C1a)*

This is also illustrated by the finding that as soon as spoken language makes headway many parents give less priority to Sign language:

> *F: To get in contact with her...eh...well, we used it intensely for about a year Now [that the child is making progress in spoken language] we are cutting down on it (C2b)*

Still we feel that to conclude that shame and shame-based evading behavior is a real issue is rather premature.

Specific issues, cases and controls

No discerning differences were found between cases and controls as both groups were equally represented in this section. Cases and controls held similar expectations of their deaf youngster as both groups focused on immediate day-to-day life and on their child's emotional well-being. Neither group overtly expressed disappointment, shame or evading behavior.

Conclusions

We found that parents' expectations were rather related to the concerns discussed in chapter three. The expectations that parents did hold of their child were highly child- and relational-centered: parents hoped that their child would become a happy individual and enjoy a satisfying relationship with his or her parents. For the most part parents appeared to continue to "shove aside" the future - with all its uncertainties - and rather focussed on establishing a meaningful relationship with their child in the present. Counselors did assume however that parents held more concrete future expectations of normalcy and they discouraged parents to cling to such expectations. In general it appeared that parents responded "well" to this plea as many of them verbalized their future hopes in terms of affective-relational values. Given these findings it seems unlikely that decisions will be aimed at "restoring normalcy" or "eliminating deafness". Congruous with Montaigne, who argued to never have witnessed a father who did not "recognize" his child however false and deformed (Montaigne 1972), most parents appeared to be not so much concerned with the image of their child relative to some abstract ideal image, be it in external society or as part of their own internal experience. Much more likely we would expect parents' attitude to lead to Sign language and deaf school enrollment.

We found no evidence that parents felt disappointed about their deaf child. Resentment aimed towards the child was also not encountered, which is not to say that parents acknowledged that responding adequately to the problems induced by deafness requires far more inventiveness and energy compared to normal children. We also found little convincing evidence that parents experienced shame towards their deaf children. Even though some of our findings - the avoidance of using Sign language in public perhaps being the most credible example - may be interpreted as symptoms of shame, alternative explanations seem reasonable as well. An important alternative explanation is that parents resent the way in which public gaze conflicts with their own relationship with their child. This suggests that parents have overcome the prejudiced narrative on

deafness to some extent and as such would argue against the hypothesis that this prejudiced perspective will frame future decisions.

CONVICTIONS ON THE STATE OF BEING DEAF

Pitiable child

If parents persist in their conviction that deafness is a catastrophe and that to be deaf is inevitably a state of sadness, one would expect that they would harbor pitiable feelings towards their deaf child. The persisting and coercive presence of such views could stand in the way of an authentic parent-child relationship.

Parents categorically denied pity in terms of how they experienced their child however. Similarly to what we described in reference to shame, parents related how they did face the normative pitiful stigma of deafness in their environment foremost, which placed them before the complex task to find a way of dealing with uninvited comments. Many parents contrasted their views with those of others who *did* feel pitiful to accentuate this:

> *F: Nothing special, just like our other kids.*
> *M: Yes, but...*
> *F: A kid with a little handicap. She is deaf, oh how terrible [sarcastic - ccw]*
> *M: Yes that is what I mean...*
> *F: But that is not the case. I think it is worse being blind.*
> *M. Yes, but the response from others, that response like 'oh, how terrible and pitiful' and...*
> *I: And that is not how you experience it?*
> *M: No, but the response by others like, eh, 'how do they do it?' Well just like you would with any other kid. (C2b)*

As we explained before, what parents seem to reject about such comments is the reductionist impact it has. What parents resent in the attitude of others appears to be that the social narrative of deafness takes a firm and rather existential hold of their child: the existential space of the deaf child is limited to this pitiful stigma.

> *F: How often did I not revolt against that. Against family members too, like oh how pitiful she is. [...] No, she is Jane first and deaf only second! (C7a)*

The social narrative of deafness reduces an individual to a stereotype, which suffocates individuality and as such obstructs authentic relationships (Wever 1997; Goffman 1963):

> *F: The three of them [deaf children] play in a [hearing] soccer team. He also scores and then they will embrace each other like on TV. In a really natural way eh, the handicap just disappears, for the hearing kids as well. You just do not encounter that a lot with hearing children...the handicap is always in between (C11)*

What parents apparently come to experience in time is that having a deaf child is, for the most part, quite similar to having a hearing child. Without wanting to downplay the

impact of deafness, it seems that most parents feel that the peculiarities that are induced by deafness occupy relatively little space in their lives. Still, it appeared that worries and grief never subside fully (Reinders 2000). When parents did speak about about grief, it was - quite contrary to the initial grief described in the previous chapter- rather specific in content. Thus, contrary to the nature of grief in the previous chapter, if grief arose it was linked to a *specific* circumstance. The occurrence of such circumstances was accompanied by pity. Still, this grief was strongly situational or contextual rather than "generic", which we feel is important to distinguish.

> *M: I still regret that it happened to him [becoming deaf] Sometimes they still ask me did you accept it? Well, to tell you the truth I would not know I am still sad about it, but on the other hand we can have lots of fun together I see that his development proceeds well...but once in a while we just hit rock bottom and you notice it again. Like now, his social integration failed, that makes me feel like 'damned, what a shame that it has to be this way...' (C12ab)*

> *M. At a certain moment we felt that it was no problem any longer for us, but then something happens and it would strike us again that deafness is a major problem. Still later things got better and we felt like: "What are we complaining about, there are worse things in the world, and it is not such a problem". (C14b)*

Parents expressed to feel sorry over what had happened to their child but at the same time expressed that they did *not* feel sorry for their child.

> *M: Of course it is a major handicap for her But if you see how much fun she is having in life, we just hope it will remain like this. (CO6b)*

This is to illustrate that pity did not intrude in the way parents experienced their child relationally. Parents were much better able to recognize the specific liabilities and limitations induced by deafness as compared to what we described in chapter three. Parents see and experience how much deafness is limiting their child's life and preview how much it will in the future:

> *M. Just seeing how hard she has to struggle to just get somewhere in this world. (C15)*

> *M: Yes you can exaggerate also I mean it has been our motive not to get another child, because deafness is a nasty handicap. Our child is doing fine, he is doing fine with it. That is great. But it is a nasty handicap. It is something you would not wish your neighbors. [...] Yes, it is terrible of course. I mean I felt like, this is terrible. Yet I am very happy with him as he is. It is a great child But for his sake I would have wanted him to be able to hear. That would have made things a lot easier. That would have made life a lot easier. So in that sense, yes is it terrible. (CO5b)*

Apparently this attitude caused parents to question if they had in fact "accepted" deafness, a quintessential question for parents of a disabled child. Parents consequently

made a distinction between the "disability" on the one side and the "affective" or "existential child" on the other: they resented the disability but at the same time loved their child deeply.

> *M: I do not know if I have accepted it, because what is the meaning of acceptance? Some link it to "loving": well in that case I accepted it from day one. (C12ab)*

> *M: I always say, you never accept your child's deafness. You don't. I find it very hard. I always say: I do not accept it, but you learn to live with it and you try to do the best for her. But that your child is deaf, you are never, never happy about that. (C15)*

It was our impression that this potential contradictory situation did not lead to the emotional conflict one would perhaps expect (Reinders 2000). Apparently parents now considered the resentment they experienced towards the disability as "morally insignificant" to their affective relation with their child.

> *M: No I do not see it as stigmatizing. Just as realistic. It would just be darn convenient if he could hear (CO5b)*

The next excerpt illustrated how "being" the handicap and "having" a handicap are separated.

> *M. She is so happy. She is not handicapped to us Of course it is a major handicap for her. But if she has as much pleasure in her life as now...that is the important thing. That she is positive in life. (CO6b)*

This is not only meant to say that the child is considerably more that the physicality of his or her handicap, but more importantly it is to *refute* the existential content of the prejudiced view on disability: this child is not pitiable, at best the handicap is.

Parents seem to achieve this by separating the trait, the "what" casu quo "the handicap" from the affective person or the "who" that their child had become to them (Isarin 2002; Cunningham 1985). By doing so parents create two separate spaces that do not intermingle: values and opinions found in one space are not automatically transferred to the other and vice versa.

> *M: Well no, we do not accept deafness. Yes, we do accept our child, but not everything around it. (C10ab)*

> *F: Yes, at a certain moment you come to see that she is a perfectly healthy child. Just look at the energy she radiates and how active she is, I am very happy with that. The only thing with which you collide is the communication. (CO6b)*

The state of the affective "who" appears to determine how parents experience their child in day-to-day life rather than the inabilities induced by the "what" of the handicap. The

experience of having a happy child and a satisfactory parent-child relationship disproves the existential claims of the negative stigma on deafness so to say

> *F She always was and still is a very joyful little girl She makes us get through it You know, she would get a lumbar puncture and after 5 minutes she would laugh at the doctor again! She had an IV 15 times 7 lumbar punctures and you would think that she would have suffered enough But no, she always kept her good spirits, the sunshine in our home! She pulled us through Of course she can be sad or angry at times but generally she is cheerful as can be (CO2)*

> *M I found out quickly that she could experience joy in life So I started to worry less*
> *I How did you discover this?*
> *M By observing her*
> *I And what did you see?*
> *M That she could laugh, that she could be happy That it did not seem to bother her much at that time she was so little, she was so flexible We communicated instantly and she never retreated, she did not think of herself as pitiful She would always say the TV is broken, the radio is broken and the telephone is broken She always blamed the outside world rather than herself (C12ab)*

From what we discussed here one would not directly expect problematic parent-child relationships, rather the contrary Indeed only one mother did disclose that she experienced difficulty in bonding emotionally to her deaf child (Eldik 1998)

> *M Her sister was a very easy baby very dear and cuddled, which made things much more natural I could provide her warmth and mother-love from my heart, while I was not providing it to our deaf child I was providing it factually, but not with passion I felt quite guilty about that (C13)*

Yet, even though this mother did make reference to a more general incompetence in "providing" for her deaf child emotionally, perhaps as the result of a lack of affective reciprocity during the early period (Isarin 2002), she also explained how in retrospect she perceived of her difficulties in terms of a coping strategy, originating in her fear that her child would not live As this mother explained further

> *M, She was very much a trouble-child from the very start Right after her birth for example, she had suspicious skin spots which set off all alarm bells oh my god, meningitis! It was never demonstrated however In any case, from the start it was uncertain if all would go well with her I complied with my duties, cobbled milk for her and kangarooed her and all that But nonetheless there was some sort of blockade between us, like I must not attach too much to this child, cause things are not going well (C13)*

Hence, the origin of her inability appears not necessarily rooted in obtrusive pitiable emotions, but rather in a sort of premature mourning reaction

Specific issues, cases and controls

The issues discussed in this section were not unique to cases or controls as both groups are represented in our discussion. More specifically, we did not find that cases were inclined to uphold a pitiable view on deafness more so than controls. Both cases and controls separated the "what" from the "who", which allowed them to deeply love their child while, at the same time, resenting the limitations imposed by deafness.

Conclusions

Parents strongly denied that they experienced pity in their relation with their child. They often illustrated this by disapproving of the pitiful attitude that they encountered in others. What parents resented about this attitude is its existential claim: the pitiful attitude stems from the negative narrative on deafness and limits a child's existential space to its negative content of "a state of sadness". Parents experience first-hand that this is an unreasonable claim, that their child is considerably more than the limitations of his or her disability. Contrary to what we described in chapter three, parents apparently did not need to conceal the real limitations of deafness to be able to achieve this perspective. Parents spoke abundantly about these limitations and how they resented them. Yet the fact that these stories of resentment were highly specific and contextual illustrates that these are different stories as compared to the stories of very generic grief that we described in chapter three. While the former seemed to be a symptom of the presence of the prejudiced narrative on deafness, these stories were rather symptomatic of realism.

Somewhat surprising we found that this new attitude did not cause severe emotional or moral conflict, even though parents continued to ponder over the question what this attitude revealed about their state of "acceptance". Parents appeared to achieve this by drawing a rather strict line between the "what" and the "who" of the child. These two spaces functioned almost autonomously; there was little transference between the two. That is to say that judgments on the state of deafness (the "what") were considered irrelevant vis-à-vis the affective child (the "who"). As one would perhaps expect from the above, we found no evidence of disturbed parent-child relationships in the sense of relationships that are obstructed by coercive emotions of pity.

EARLIEST DECISION MAKING: LANGUAGE & EDUCATION

Introduction

In the previous sections of this chapter we found little evidence that the profuse and generic sense of tragedy continued to be of much influence on parents' outlook as time passed by. This finding refutes one end of one of the hypothesis that we wished to test in this chapter: early parental responses do *not* appear to consolidate into something that we could consider to be an "attitude". As such the suggested link between specific "attitudes" and decisions that are aimed at "restoring normalcy" is defused. Still, it may be that our empirical material does not allow us to illuminate the attitude under question. After all, we mentioned that the items that we were probing for in the previous sections are socially sensitive and as such vulnerable to narrative transformation. In addition, particularly our discussion of "shame" did not unequivocally prove the attitude thesis as being false. This implies that we need to consider the actual decisions that parents took as well.

Parents of deaf children face several momentous decisions in the first 2 or 3 years of their child's life. The first issue that they will have to decide on is the issue of language, a decision that must be taken almost immediately. The second issue concerns the choice for a school. Even though this latter choice can be deferred for some time, logistics often imply that language and school choice more or less coincide. Even though today all Dutch schools for the deaf are obliged by law to offer a bilingual curriculum, this was not the case in the late 1980s to early 1990s when most of our respondents faced the language issue. Back then parents could option for a mostly manual- language approach, offered by most schools for the deaf as well as many schools for the hard of hearing. Alternatively they had the option of a mostly oral-language curriculum, offered by the IvD as well as some schools for the hard of hearing.

In this section we will describe the language and school decisions that parents actually made. We will draw the general landscape in which the decisions were set. Did parents feel emotionally prepared to make such decisions? Did they feel adequately informed when deciding for their child? Subsequently we will ask parents specifically to explain to us how they reached their decisions.

Preparedness and readiness to act

Simons has argued that parents of a disabled child are "overwhelmed" by their emotions, which instill a state of freeze.

> The assault is so great that most parents become paralyzed Weighed down by their feelings, they become incapable of making decisions (Simons 1987, 7)

Given the intense agony that parents described in chapter three, such a hypothesis does not come as a surprise. However, our study design does not allow us to measure such an emotional paralysis directly. All we could do was ask our respondents if they felt emotionally and cognitively prepared to make the substantial decisions they faced, often very shortly after the diagnosis was established. Our subjects did not support Simons' thesis however Quite to the contrary, the awareness of the need and the preparedness to act was generally quite large indeed.

Parents recognized that grief, in the sense of an inability to make decisions and take action, would not benefit their child·

> *M How did I react? Well, terrible of course, but we have to go on[ ] You can of course walk around all day with a sad face but that will do no good From the start we had the attitude that we must go on and deal with it (C2b)*

Besides the potentially paralyzing grief that parents experience around the diagnosis, the lack of knowledge is a second factor that could jeopardize the ability to make a sound decision It seemed however that parents respond to the lack of knowledge almost instantly Parents realized that their prior knowledge was hugely inadequate to deal with the problems they now faced.

> *I Can you tell me what happens to you as parent when your child turns out to be deaf?*
> *F A sandbox*
> *M Yes! I wanted to say*
> *F It is like coming from the highway at high speed, down hill, straight into a sandbox (CO5b)*

Parents were often information-hungry and gathered information in the library, the Internet, through experiential experts or professional counselors.

> *M Well, we bought a lot [of books] and borrowed literature about it [deafness] (C12ab)*

> *F We had an information frenzy, we called all around like how do you deal with this or that and explain this or that to me (CO5b)*

> *F First we contacted people, people we met at conferences that we attended And we searched for titles through the index in the library*
> *M Read books, yes*
> *F We ended up reading books, general books discussing deafness in a popular scientific way (CO5b)*

F You have to make sure you make contact with peers with the same problem exchange information (C5a)

M In the beginning I wanted to know everything there was to know you know it was completely new for us, we did not know anything (C8b)

Parents' awareness of the need for something to be done appeared rather instant Parents stood open to and were highly motivated for change Apparently these parents perceived of deafness as a state in which "change" was possible indeed, at least they must have assumed that knowledge and certain decisions can make a difference One parent made a comparison to parents of children with a mental handicap in this context

F I mean if you have a mentally retarded child they grow older but nothing changes It seems to me that the sense of powerlessness is much greater in such a case (C9a)

Some parents were so eager to act that they felt "slowed-down" by their counselors, who assumed that decisions could wait and that parents needed time to digest the situation emotionally

M She was still in the hospital when we first visited the local deaf school My husband said to the director I have a deaf child but what do I have to do?' He replied that we should slow down get over it first and then proceed (C4ab)

M I wanted to know so much but could not get the information anywhere
I Not from the social workers?
M They told me to first take time to get over the whole thing, because there is so much information and they gave me no information at all while I was in need of something to read, a video tape or something (C8b)

F She [social worker] said like do not go too fast
M Work through it first
F Think about it and work it through But we were like we have to start working (C14b)

Parents thus exhibited a strongly "problem oriented" way of dealing with the situation They considered the situation a "challenge" rather than experiencing helplessness and freeze This attitude is generally associated with positive child rearing behavior as compared to "resigned" coping (Rispens 1996, Dekovic 1996) Yet the possibility resigned coping was also touched upon

F We were on top of things Those early years were not easy but we were on top of things I think the level of engagement makes a difference I mean back then there were quite some kids who just attended the boarding school One progress conference every three months that is it!
M We were talking with her teacher every week! (C9a)

Some authors have suggested that this strong drive towards information gathering is to be interpreted as a coping strategy rather than an effective problem-solving attitude, the difference being that the former is not primarily aimed at tackling the problem at hand but rather to silence the agony induced by powerlessness (Isarin 2002). Indeed, the diagnosis of deafness may induce a profound feeling of inadequacy and helplessness or powerlessness. In turn this could be argued to induce a "compulsive" need to act, to subdue the former emotions so to say and regain feeling of control (Spink 1976). Spink for example, explicitly includes "rationalization" of problems in her description of parental coping strategies (Spink 1976). One parent underscored this position:

> *M. Everyone has his or her own methods. Mine was to gather all available information immediately and stipulate strategies, strategies to escape. . (C13)*

For most parents however information gathering and rationalizing appeared as a rather normal problem-solving process, which does not contest however that parents did feel insecure or highly emotional. As we also discussed in chapter three, many of them did.

> *F. You are out looking for certainty. You are looking for, you're just immensely insecure about what to do... (C11)*

> *M: So, we succeeded in rationalizing the emotions and just started working at it. (C11)*

> *F: In itself it is OK if they [teachers and social workers] tell us that things are not going well, but it is the way that the message is presented. I cannot do anything with the message "things are going wrong". There needs to be an addition to it like: "things are going wrong and so...we are going to do this or that exercise..."(C9a)*

Yet only few explained their hunger for information in terms of coping with these emotions *primarily*. It seems that Spink's theory is based on the assumption that there is no good reason to feel an urgent need for action in the case of deafness, which leaves the omnipresent emotional agony and feelings of inadequacy as the most likely targets of such an urge. Yet there *are* sound reasons to experience an urgent need for action. As we discussed in chapter three, the need to establish communication with one's child seems rather profound and urging to parents. Perhaps this is aggravated by the diagnostic delay that occurs in most deaf children, which could give parents the feeling that they are backlogged as it is.

Quality of information

In search for knowledge parents turned to specialized services that were readily available to them. In general parents were content with these services, in particular their support in working through the experience was much appreciated. Yet in terms of information about deafness itself, many parents said that the much-needed encompassing information basis

was not provided to them but was rather left up to their own initiative to discover (Menzano 2000).

M. They told us we had to arrange things ourselves. (C4ab)

M: I went to speech lessons, just for inspiration, and there are all kinds of games: word games and such which you can do at home as well But you really have to do it yourself, nobody brings it to you. (C11)

I: What kind of information did you get? Was it clear, allowing you to act swiftly?
F No
M: No
F: No, you really have to find things out yourself. The technique, the explanation and eh, the philosophy behind their way of teaching, their way of teaching to read and speak. We had to gather this from books...(CO5b)

Not a single institution provided encompassing information in the form of a general framework of available options spanning infancy, childhood, adolescence and adulthood, a finding also reported by Menzano (Menzano 2000). The broader dilemmas are apparently not touched upon in this phase. Yet some parents denied this situation.

M: The counseling [at an audiological center] was very good although the information could have been more expansive. But they made every effort to take us to the different schools, discuss the options...
I: Did they explain the different schools in the Netherlands?
M: Yes, yes.
I: The difference between IvD and Guyot?
M: Yes, yes.
F: We visited there.
M: We went to see for ourselves Those opportunities were available. (CO6b)

Information tended to be restricted to the local curriculum. Oral oriented counselors were inclined to defame signing schools and the other way around. One mother for example, who expressed her preference for Sign in discussions with her oral oriented counselor, was told:

M: They said: well Effatha or Amsterdam [both signing schools] are an option. They find it lovely that they are deaf! (C11)

Consequently, many parents who consulted one of the signing institutes were unaware of the availability of an oral program in The Netherlands and vice versa.

I: Did they inform you of the availability of an oral program in The Netherlands?
M: No, they did not...

F. If we knew that? I don't think so. I do not think we knew that there was a school for the deaf that offered an oral program. (C9a)

M: And also like, we have to raise her in sign. I mean this was advocated by the audiological center...
I: Did they speak about the option of spoken language?
M: Yes, but not until later (CO4b)

If parents were aware of different options, it was mostly the availability of an oral program at IvD that attracted their attention. Several parents that primarily consulted one of the signing institutes considered IvD as an option (CO3, C7, C9, C10) and two parents actually transferred their child to this school (CO3, C9).

It would seem that if this description is correct some parents unavoidably will not succeed in looking beyond the standard information with which they are provided and therefore de facto base their earliest decisions on this information alone. Some parents indeed underscored this:

F: We will have to raise her in sign. The audiological center advocated that. And at that moment you just adopt such an idea. If they would have told us not to sign but focus on lip-reading, we probably would have adopted that too. It is your only reference frame at that time. (CO4b)

F: We are able to make independent choices relatively well I think. But eh, we have talked about this, if you succeed less in acquiring information you will likely let decisions be made for you. (C11)

M. We did not know any better. We did not know about other schools, about programs based on spoken language. We did not explore that.
F: But it is also...one is ignorant really. [...] You do not have much of a choice really. They draw a picture for you: this is it and this will be the future (C9a)

As argued, many parents did collect information single-handedly. Yet the information that they encountered did not appear to produce the clarity that they had hoped for. Parents said that they were bewildered by the conflicting information (Menzano 2000). Parents were thrown in the middle of the method-battle that we described in chapter one.

F: We wanted to know everything but only found that there were two worlds.
M: And which way were wé to go? Did we have to sign? Was it better to insist on speech? (CO5b)

M: So we landed in the battle between Sign and oralism, that kind of thing.
I: How did you?
M: Through the library. One of the first books that I read was an American book. I have never encountered it again That [book] was sort of an assault against oralism, because

they it was full of propositions After every chapter a list of propositions Next I read the book by Van Uden [Dutch advocate of oral education-ccw] and had many conversations
F You are looking for certainty you are deeply insecure about what to do And what happened was that instead of authority such a discussion uncertainty was brought to us That is not good for parents in such a situation [ ]
M I remember saying it is like they have just discovered deafness! (C11)

Not surprisingly and congruent with literature, parents sometimes recounted that they had felt very much abandoned (Philp 1982, Simons 1987)

M I felt lonely and isolated at home (C4ab)

Simons also speaks of feelings of being "alone in facing problems", yet explains this from the perspective of the parents themselves

> They know that help is out there but they are unable to pick up the phone to ask for it (Simons 1987, 7)

We did not find convincing evidence in support of this position Rather it seemed that parents were genuinely abandoned in their suffering Parents know that action is much in demand and in spite of their inner suffering are prepared to act, yet they are inadequately supported in doing so Professional help appears to have a very fixed notion of "what is needed" in this period The focus is on parents much more than it is the child Without wanting to claim that this attention to the coping process itself is redundant, it does seem that many parents desired more attention to deafness as well

Choosing for Sign language

In spite of the confusing information that parents gather vis-a-vis deafness, they *must* choose a communicative medium rather swiftly Indeed parents were highly motivated to establish a means of communication and most actually did make decisions surprisingly fast With the exception of two cases (C1a, C3b) all respondents chose Sign language as their medium for communication C1a aimed for an oral route early on while C3b was approached through finger spelling Most parents commenced with courses in Sign language within only weeks after the diagnosis (Sloman 1993)

M We enrolled in a Sign language course almost instantly really within two weeks [after the diagnosis] (C13)

F We got our act together very fast In June she was attending the deaf toddler group we started that immediately I think that as soon as June or July we were attending a Sign language course (C9a)

M: We immediately focused on Sign. I remember, she became deaf in March and got out of the hospital by the end of May and soon summer vacation was around the corner. So by the time we went on vacation we were able to use some Signs with her in addition to pointing and speech. (C10ab)

M. Shortly after we found out [about the diagnosis], he was 11 months [at diagnosis] and with 13 months we were signing. C14b)

The fact that parents almost unanimously chose for Sign language may come as a surprise given what we discussed above. Yet several factors seem to explain their choice.

First and foremost the advocacy of Sign language as the language of choice for young deaf children appeared rather widespread. It appeared that even oral-oriented institutions advised parents to take Sign language classes: the method controversy is deferred to later developmental stages. All diagnostic centers in the Netherlands actually offered Sign language courses for parents.

Secondly, learning Sign language is one of the very few concrete things that these parents, who wanted to do something so much, could actually do. As we argued about information gathering, the early submersion in Sign language also appeared to yield positive effects from a coping perspective. Engaging in Sign language courses "empowered" parents, reimbursed their sense of control (Isarin 2002).

M: Well, I realized rapidly that something had to happen, and that is Sign language right? (C1a)

M: It was an enormous step, but once we took it... We were given a Sign language book and they [audiological center] helped us with it. Once we told them what we wanted we were given a Sign book. I remember the first night when we did the animal signs, him [deaf son] included. With pictures and such...we really had to work hard. It was a lot of fun though, to be busy with it. From the very beginning, a sort of...
F. Yes, you could do something together again.
M: Yes. (C11)

M: They [counselors] felt that I was going too fast, being too rational with it. They told me I should process it first, that was even advised like: some people stay at home for half a year, why don't you? [...] But I could not. The only thing I could do was to learn Sign language as fast as possible, get to know where the schools were. Read about the Deaf community...get video material, every thing that I could find I would get...(C13)

Thirdly, and related to the second point, the discourse surrounding Sign language advocacy appeared to yield a "close-fit" with the values that parents themselves held in this developmental phase.

As we mentioned before, parents' prime aim appeared to be to facilitate communication as soon as possible and, through this, establish a fulfilling parent-child bond In itself this is not so surprising. The intensely emotional-relational attitude of modern parents towards their young children has been addressed abundantly, intimacy has become one of the prime parental goals, particularly during early childhood (Jacobs 1993b) Parents seemed to hold that Sign language was the only or at least the most effective communicative means to realize this

> *F Well, I think she [oral deaf peer] has a vocabulary of about 80 spoken works, but our daughter has, what 500 to 1000 signs? Now, what do you prefer? (C13)*

Communication through the conventional oral-aural channels, although in some cases relatively successful, seems destined to be less efficient than communication through a visual language channel and parents sensed this intuitively. Therefore, the choice for Sign language was commonly grounded in the desire to improve or facilitate early communication. speed up the rate of communication, increase the content of communication and lowering the child's threshold for communication so to enhance the parent-child relationship

> *M We chose for Sign language to get contact with our child We were having contact with her, yet we wanted more contact, faster communication (C2b)*

> *F We realized that the oral strategy delayed communication by years Maybe it allowed better-spoken language ultimately, but at the cost of a delay in communication We found that to be an unacceptable alternative (C11)*

> *F We did visit the Sint Michielsgestel institute We came to the conclusion that we should not enroll her there We felt that we could tell her all kinds of things with Sign while those kids were sitting there and the teacher would be 'bla, bla, bla' [ ] We did see some older children as well and saw that things did improve with time But not before they are 6 or 7 years old She was only 3 and we could communicate with her We were really happy that we did not have to wait that long (CO4b)*

In particular during the early child years, the delay in language is likely to be significant if only spoken language is provided, given the high threshold Learning a system to which logic one is blind will likely be a slow process, at least up to the point that the logic is unraveled so to say Consequently many parents perceived of Sign language as the perfect means to bridge this early period

> *M You just have to bridge that period when it [spoken language] does not work, is not enough, that speech is nowhere yet (C13)*

> *M I feel that if a child is deaf you cannot do that [communication through speech] to them during their earliest years, because they can only see, they won't understand it (C14b)*

F It is just so logical [to use sign] before you teach them the trick of speech And the long road to it, before then you need contact (CO5b)

M Communication is of the utmost importance and we had none back then We had no communication If you hear about the past, children succeeded in communicating with their parents in adolescence! [ ] We were very happy when we heard about Sign language Like wonderful, we can grow towards her 'cause you know all to well that spoken language goes very slow She will succeed, absolutely, she will succeed but you have to wait so long before you can really reach her (CO6b)

F We realized that the oral method leads to success after many years Maybe he would master spoken language but after a longer period, during which they are unable to communicate We felt that was an unacceptable alternative really (C11)

The poor outlook of an oral approach was sometimes experienced hands-on. Some parents who visited an oral program, recounted.

M Well, we did not feel that they spoke well
I It was disappointing?
M Yes, it was rather disappointing We visited there with high expectations, like now we'll see speaking deaf children like let us see how well they speak and we were disappointed greatly (CO6b)

F So the first deaf person I saw was "a showroom model" as I always say, we met them there [signing school for the deaf] Well, we were startled enormously
I What did you see?
F Those who could speak, well they said Well, we did not think so at all (C11)

Taking the examples that they witnessed as the maximum achievable by deaf children, these parents appeared to have been affirmed in their view that the oral approach was out of the question:

F I feel it was good It was wonderful that it became clear (C11)

Indeed many parents told us that the introduction of Sign language resulted in vastly better communication, thereby satisfying one of their main objectives

M He picked it up immediately very fast indeed
F And that really made a difference in our communication with him When we learned to sign our communication increased a lot (C8b)

M Really, she started to sign back at us within a week and yes it was wonderful, she really blossomed
F It is funny on all baby pictures up to a year and a half one can see her frown I make from that that she knew very well that we had something in which she could not

participate And when we started to sign you could see her frown disappear and see her blossom and realize like 'hey I have contact ' (C13)

M Before he used to look so sad and pitiable and when we did that [sign] he really flourished from the start he became a different child all together (C14b)

Consequently parents also reported instant relational improvement as soon as Sign language was introduced

M Suddenly there was contact between us a totally different level of contact really (C13)

In spite of these advances Sign language did not erase all communication problems instantly, emphasizing that the choice for Sign language requires significant and persistent investments by parents More abstract notions such as time and space continued to be a problem Many parents related, for example, about how difficult it was to explain to their child that they were going to leave for a while

F He never understood what we wanted or what we were planning to do which would make him cry all the time When we would pick him up [to leave] we could not explain first we are going to do this or that or we are going somewhere We could not explain that [ ] If you cannot explain and he does not understand, he would not accept it that we left We experienced that so often if I would leave by myself on a Saturday he would stand outside for an hour and cry
M He was angry then
F He would not accept it, that you could not explain why you were leaving and for how long, because time is important and time, time we could not explain How long, how many hours or eh half a day that was hard to explain [ ] (C8b)

Expressions of emotions were also found difficult to communicate

M They [Sign language instructor-ccw] taught it to us First you ask you child 'finish your food" Next "you really have to finish your food' Then "finish your food right now!' So we had to exercise, eyebrows in normal position, a bit angry by raising one's eyebrows a little and very angry by opening your eyes widely (C13)

M You start with the simple things, a table or chair and other tangible things and that is easy But then come the difficult things such as emotions signs [ ] (C11)

Bornstein found that most hearing parents of deaf children never reach beyond an elementary mastery of Sign language (Bornstein 1980) Swisher has shown that this backlog persists even in the most motivated parents (Swisher 1985) Beck states that Sign language proficiency varies widely (Beck 1996) Indeed when asked about their level of proficiency most parents revealed that this could improve Even one mother who was a

registered Sign language translator said that she had difficulty following conversation in Sign between her child and another deaf infant (CO7).

> *I: You learned Sign language, almost immediately, took courses. Do you feel that you master it?*
> *M You mean really perfect? No not really. But we get by and that is the most important thing. (C10ab)*

> *F: Just like she will never learn to speak real well, we will never sign well. I mean, it is a true tour de force for us to do that with finesse. It surprises me to see how fluently she signs and how logical that is. It makes me feel like such a wretch, even though we are not bad at it I think (C13)*

> *M: When one starts learning Sign language one will think: "how will I ever master this"? It is so difficult, so difficult. (CO6)*

Parents attribute their unsatisfactory level of signing skills to several factors, the complexity of Sign language and the relative little use they make of it being the two most common explanations. Notwithstanding the fact that many parents said to have only modest command of Sign language, most considered their communicative relation with their youngster satisfactory.

Another problem that was difficult to solve, if solvable at all, was the level of engagement of the deaf child in his or her home environment (Beck 1996). Bodner-Johnson found that the informal communication around the dinner table is rather limited and mostly restricted to answering concrete questions (Bodner-Johnson 1991). Hearing family members tend to exchange ideas in their normal oral-aural mode when not directed at the deaf child specifically, yet this "normal mode" is beyond comprehension of a deaf child of course.

> *M: I still feel the pressure even now. Like, I am not doing enough; I have to involve her more. Sometimes one has lengthy discussions at the dinner table and you are just not comfortable about the whole thing, I think: no guys, we have to involve her more [...] Sometimes we will be having a discussion at the table and she is watching TV from the couch: "you guys are talking right?" (C10ab)*

> *F: We sign if we are addressing him, but if I am addressing my other children I forget to sign.*
> *M: It is wrong. But you can't escape it if you're busy...(C14b)*

Some parents felt that the language deprivation that would result from delayed language development if an oral route were chosen was harmful for several reasons.

Mastering language at an early age was in itself considered crucial from a psycho-emotional perspective.

F We feel that communication in early life years is essential, getting information, for the development of the brain, for the development of the self and self-image, love and self-consciousness [ ]
M I remember that I read a pedagogical text around then, by Selma - what is her name? - a well-known text Magical world of the child [likely Selma Fraiberg's The Magic Years - ccw] It contributed a lot to my final choice for sign, because I wanted him to be able to communicate early on
F Communicate, yes
M [ ] I felt it was important for his social-emotional development to be able to communicate early on Because this book is not about deafness at all, it is purely a child-psychology text I think (C11)

But a delayed language development was also seen as the source of a variety of other problems. Orally trained children were, for example, postulated to have difficulty in mastering complex language tasks, particularly emotions.

M She does all right [with experiencing emotions - ccw] Thank God, thank God, because many deaf people have little emotions you know? But she does, compared to peers I think, she can cry when the grandpa of a friend dies, she feels so sad about that, that she cries Yes, really sensitive you know? Because, at school when the father of a student died the teacher told me that his child did not even cry, nothing How terrible Another mother told me that when they returned from vacation and the dog had died that her deaf daughter did not cry, nothing! Her hearing brother did, but she did not Well, if I look at my own daughter and see how she can cry about things, especially when someone dies, she feels terrible and cries like a rainstorm That makes me very happy, like, that child has emotions (C10ab)

F Yes, they assume that they are deprived emotionally because they never had the opportunity to develop emotionally through that language-instrument (C5a)

M A child must be able to express his or her feelings and they do that best in Sign language We feel that way (C14b)

F Of course a deaf child proficient in Sign language has abundant means to express him or her self, and hence will not become frustrated He or she can express emotion, can express thoughts and that is very important of course (C6)

Emotions of course, are an important ingredient of a satisfying parent-child relationship. As such the concern over emotions may be related to parents desire for a gratifying parent-child relationship

A delayed language development was also reasoned to result in a lack of (emotional) nuance The lack of nuance, particularly regarding the aforementioned emotional arsenal, is a topic that is found in literature as well (Paul 1993). Some parents underscored these theories with direct observations.

M I mean, my son's development, well it was limited to basic emotions, like anger sadness and those kinds of things but just few greys you know? It is not like 'in ten minutes" but "yes or no" We visited the FODOK parents' day and saw all these little signing deaf children who did succeed in expressing themselves This in contrast to my son, well, because he did not master spoken language well back then (CO5b)

M For example she says "I want this, I want that" in Sign language We respond "you can ask like 'could you please do this for me?' or may I please?'" But still, everyday she is like 'I want this" (C13)

M You just notice that with a deaf child it is either you are angry or you are very sweet there is no middle road (C14b)

M Yes, yes, the greys are not there
F No, no greys
I In her way of thinking?
F Yes, very black-white Deaf children, at least my daughter, is very black-white Good or bad, not more (C7a)

The concept of "mother languages" sometimes appeared in this context With this concept parents expressed their conviction that one can *only* experience and express nuanced emotions in the language that one learns first. For deaf children this translates into Sign language.

M Sign language would become such a rich mother language for her that she could express all her emotions and internal feelings [ ]
F It will always be her first language, sign Just because it, it belongs to her And the first language one learns is ones mother language (C13)

Yet parents also viewed the oral environment as one that could hurt their young child due to other causes than language delay. The idea that an early oral language approach in itself would yield an "injured child" was rather wide spread On the one hand this notion seemed to spring from the idea that orally trained children must confront their inabilities on a day-to-day basis. By perpetually confronting children with their inability, negative impact on self-image was seen as inevitable. Exposing a child to a rigorous training program in which they are "forced" to do something that is rather difficult to them seemed to draw instant aversion.

M We visited IvD We found that these children had to speak to much, repeating all the time We felt resistance against that [ ]
M All the kids had to tell what they had seen in the Zoo They had to make perfect sentences, the sentences they produce were not good enough They had to listen nicely, it was corrected in decent Dutch And then they had to repeat again And then it would not be good and they had to repeat again (CO6b)

Parents seemed to perceive the pedagogical environment induced by oralism at odds with how they apparently viewed an "ideal" environment for a young child. The pedagogical effort that oralism required was deemed harmful since it robbed children of their childhood so to say, transformed children into "students" at a premature age.

On a broader view, parents felt that it was beneficial to their child *not* to be exposed to the negative stigma on deafness at an early age. As such the choice for Sign language seemed to function as a proxy for a protective environment in which a child is not, or not as intensely, confronted with the stigma of deafness. A deaf child that is fully submerged in Sign language will typically attend a signing deaf school and will also sign at home. As a result, the confrontation with the stigma of deafness is postponed or soothed somewhat, a situation that was interpreted as beneficial to the child's self-image.

> *M I sense that it is important for her to be amongst other deaf people in her childhood. Most of all to gain confidence (C11)*

The concerns that we discussed above were fuelled by stories of orally schooled deaf adults. These narratives seemed to be perceived as "empirical proof" of the damaging effects of oral training.

> *M: We visited Deaf clubs in Arnhem [Dutch city]. We encountered Deaf people there and heard them speak about the past. Also about the negative experiences, having to speak all the time and not being allowed to use their hands (CO6b)*

> *F. The big drama that Sign was abolished for 100 years, we sensed that...[...]*
> *M: We knew a boy who grew up at IvD, so was raised orally and now he wanted to learn to Sign because he could not deal with spoken language. He was terribly frustrated and angry and all, that he was obstructed in his development for so long. It was really clear to us· just look at him. One should not do that to a deaf child, to provide him with only pointing and pulling for so long. That gives enormous emotional problems, we just did not want that responsibility. [...]*
> *F: I am still a passionate opponent of oral education. Because I think you lose valuable time in a period when the children are maximally sensitive to language. (C13)*

All the arguments that we discussed so far appear rather pragmatic in nature. Parents' preference for Sign language thus is primarily explained by their conviction that this mode of communication was best suited for the problems they encountered in their actual situation. This is also illustrated by the finding that if parents succeeded to establish a satisfactory relation with their child, which occurred in some of the children who became deaf between 2 and 3 (C4ab, C1a), they felt less urgency to engage in Sign language.

> *M: We never really experienced difficulty in our communication with our child We understood her quite well and she learned to lip-read quickly. We considered Sign language, but concluded it was not needed because of our communication. If our*

communication would not have been this good, we would have picked up Sign because you want contact with your child of course. (C1a)

F: I realized that I needed to learn sign ..If things would not succeed with lip-reading and such and if communication would stagnate then I would come to need sign.. It was more in case of emergency, like in case that we would need it [in the future - ccw].[...] You really have to look at the individual child. Try it if it fails I would have no trouble at all resorting to Sign language. (C4ab)

Still, one wonders if parents did not fear the long-term consequences of their decision, for example the risk that by choosing for Sign language they could compromise the opportunity for spoken language acquisition. On the one hand we feel that this was not the case. Parents seemed much involved with the *actual* problems they encountered and were trying to define the best answers to these specific problems, which is not such a strange finding given the magnitude of these problems. However, if we bring back into memory what we said about the lack of encompassing information, one could also suggest that some parents may simply have lacked the information to visualize the potential liabilities of Sign language. Our material suggests an alternative explanation however. It appeared that quite a few parents were counselled in the direction of "bilingualism". The bilingual thesis steers clear of the potential discordance between manualism and oralism: it presents itself as a "win-win" situation. One parent couple who visited a signing school for the deaf prior to deciding at which school to enrol their child, were even presented "successful" speaking deaf pupils (C11).

M. That is the way I think it will be with her too. In the future she will learn Dutch perfectly but we will still have our language together and that is Sign language
F: I can even imagine, it is logical, that if she is doing fine with Sign language and her Dutch also starts to develop...I can imagine that in time she will be mainstreamed. [...]
M: I think they [deaf children in bilingual programs] will catch up [with deaf children in oral programs] around age 9 or 10. that is what they say at her school, that is their experience. I think they will learn to speak at least as well as at IvD. (C13)

M: He would stay at the Amman school, would learn Sign language and after some years would learn to speak His signs would diminish; at least that is what they told us. Later on they will learn Dutch, which will allow them to be mainstreamed easily. (C14b)

M: It has been proven extensively that if you master one language it becomes much easier to learn a second and third language Because you have access to the grammatical structures. (CO1)

As discussed previously, bilingualism departs from the notion that providing a solid first language basis will facilitate second language acquisition, be it in its spoken or written form (Beck 1996).

M I think that the balance will even pivot to the other side eventually Because children who have been raised orally have to wait so long before they master words and only after that you can start making structure, learn grammar If it is delayed for so long they will miss the boat While, at least that is my theory, if they learn the grammar of Sign language immediately in a good fashion they will build their Dutch on that [ ] But they have to learn it in the sensitive period, between 3 and 7 or so (C13)

F We read literature and got information from the institute [signing] They said that speaking and lip-reading could take place parallel to Sign language very well Not as good compared to if she would have attended an oral school perhaps, but good enough to function in hearing society we think [ ] I think she will be able to function in hearing society [ ]
M Did I tell you about the bilingual group she is in? The basis is Sign language and from there they want to teach her Dutch
I And how are things going with Dutch now?
M Not so good I think But it will come (CO4)

F [Sign language] is the basis of your communication From there you can proceed with spoken language But then there are those other theories [which other parents uphold] that if you start with Sign language, spoken language will not develop [ ]
M I am not convinced of the claim that Sign language induces worse oral skills, that they will speak worse (CO6b)

Parents who chose for a bilingual program never did so because they did *not* value spoken language If spoken language skills were below par, they still held strong hopes that this situation would improve

I What do you hope?
M What I hope? That she will be able to speak intelligible, intelligible to hearing people
F And reading and writing
M Yes, you just hope that hearing people will be able to understand her What we expect? Well that things will be all right with her speech Given what she knows in terms of words and letters Our expectations are quite high (CO4b)

Yet a few parents went beyond pragmatism and explained their preference for Sign language in a rather encompassing way A prominent element of this justification was the assumption that deafness is a "cultural" or "existential trait", for which reason we will label it as a Deaf Culture Identity (DC-ID) view We encountered this view most expressively in two parent dyads (CO7, C13)

M Regarding the Deaf world it was clear to me to us, that they have their own identity and culture and I understood that the center of that activity was Amsterdam So if you want your child to meet Deaf adults so he or she will not think that he or she will suddenly become hearing at some point in time, and if you want your child to find and respect Deaf identity you have to move to Amsterdam and make sure he or she attends all those things like the child-club and making sure that there are deaf friends around You have to

submerge her. That is her world and the world I wanted to get to know, we wanted to know...(C13)

The concept of "mother language" resurfaced in this context. One parent appeared to link the concept of mother language to "feeling at home". Indeed it seems that if one assumes that man can only feel at home in his or her native language and if this native language is Sign language by virtue of the pragmatic arguments discussed above, Sign language becomes rather mandatory.

M I lived abroad long enough to know how it is to be able to speak your own language, because that is the closest language. There is no language that means so much to me as Dutch I can feel that if I have to speak English a couple of days in a row I can physically feel than that it is Dutch that I speak. I know the same about Frisian people. I used to live there and I know it [...] They can feel Frisian, it is closer by It is the same for him [deaf son]: he is signing child. That is his language. That is his mother language. (CO1)

Still the validity of this assumption is questionable. After all, there are many people who - through immigration - are placed in a situation where there is no access to their mother tongue and adopt a new language. To assume that these people must suffer existentially seems rather preposterous.

Yet we also encountered arguments that were an "extension" of the pragmatic arguments that we described above. That is to say that we found some parents to utilize similar arguments as discussed above, but with the tendency to consolidate or transgress time. While some parents pragmatically felt that it was better for deaf children not to be confronted with stigma at a young age, others seemed to reason *beyond* the boundaries of age. In hearing society deaf people will likely be confronted with stigma, *whatever* their age.

F: In our neighborhood he is always different. (CO5b)

I: What is the benefit [of deaf-deaf relations] in your view?
M: [...] Amongst deaf children he is an equal while [amongst hearing peers] he is always seen as the lesser one. (C12ab)

This was true also for the valuing of peer-relationships. Some parents felt that peer-relationships were important because they facilitate "shared experiences" to be established. Apparently parents felt that being deaf calls for experiences to be shared.

M. She has a deaf friend for about 6 months now...how those two attract each other, that is different.
I: Can you explain?
M. They understand each other better than a hearing person and a deaf person do, they're both deaf, yes...a feeling they have, they recognize each other...they intuitively sense each others problems. (C1a)

M: But for him it is a good experience once in a while to be with his deaf friends playing with deaf children. He loves it. I mean, it is not like he is having such a hard time in his neighborhood. But you just notice that they are..eh...all the same there He just likes that. once in a while. (CO5b)

M: She has a deaf friend who travels to school with her. One day they had a terrible fight. We talked about it and I told her: it is not bad to fight, as long as you make up. "But I do not want to make up" she said. I replied: I understand that...but you have to try to make up because he is the only friend you have that signs, you understand each other and he is really important for you. "Why is that?" she replied, she disagreed. "Well", I told her, "because everyone else around, besides us and her sisters, do not sign. So you depend on him a little". (C13)

Parents suggested that friendships with deaf peers are more meaningful than those with hearing children:

M: Sometimes she will be sitting here at home with hearing friends and still calls a deaf friend and says: "will you come over and watch a movie because I am so lonely". It is like, it seems all right, she has hearing friends and it seems as if she feels fine but she apparently does not. Why else would she call a deaf friend if she has 4 hearing friends with her? (C6)

Another issue that was raised in this context was the presumed symmetry or reciprocity of deaf-deaf relations. This issue is also likely to transgress time, since even the most successful oral deaf are likely disadvantaged in their communication with hearing people. The ease and fluency of communication between two signing children is unlikely to be matched in a deaf-hearing context, however successful one is at mastering speech.

M: I see how other [hearing - ccw] children have difficulty in making contact...[...] they can be really tough on her. (C2b)

F: It [Sign language - ccw] communicates really smooth you know...(CO5b)

M: He does not have to walk on his toes [with deaf friends]. And he can talk about things that he cannot with hearing peers (C12ab)

F: Even if she learns to speak well, it will still be difficult for her. (C13)

M: He just cannot say what he really thinks or feels.
I: Why can't he?
M: Because of his communicative problem. [...] Because they [hearing peers] cannot sign and he can speak but his vocabulary is too limited for a ten year old, that is the bottleneck. (C12ab)

M: I still socialize with some of the women that I met at my pregnancy-group and the children will play around. But I can see him [deaf son] sitting in a corner, at a distance,

just looking on Not playing, not engaging He feels at unease Perhaps he already feels that he cannot follow it all (C14b)

It remained unclear however if the DC-ID discourse was "primary" in the sense that it truly determined parents' path up front, or that it functioned as a proxy or "moral filler" If indeed a primary motive, one would perhaps expect that individual capacity for spoken language acquisition played no significant role Yet there was some evidence that it did One of the most fervent DC-ID oriented controls remarked

I What if you had been able to communicate with her through oral language do you think this could have changed your path?
M I think so yes I think she would have been in hard of hearing [school] (CO7)

Another strongly DC-ID oriented dyad (C13) were the parents of a very young child who had made no progression in spoken language terms at all compared to other children in this survey this child exhibited very little inclination towards spoken utterances while the need for communication was apparently rather large Furthermore, these parents were also paraphrased as pragmatic advocates of Sign language, "to bridge the early childhood years" It may thus be that parents try to avoid negative choices ("we chose for Sign because our child cannot speak at all") and therefore adjust to a positive narrative that accommodates the actual situation DC-ID is successful at achieving this

Specific issues, cases and controls

If we look at the characteristics of parents in response to the several topics covered here, some trends may be tentatively depicted While parents from northern and western regions (at the time of the interview) were also over-represented vis-a-vis the "pragmatic" reasons to choose for Sign language (about 70% while 55% resided in these regions at the interview), the responses to the bilingual and DC-ID issues were almost *exclusively* the product of these parents 80% of parents quoted about bilingualism and 100% quoted about Deaf identity resided in northern or western regions Moreover the three dyads (CO1, CO7 and C13) that we paraphrased on the topic of Deaf identity were also Sign language advocated on a national level Parents that engaged in "extended pragmatic motives" were represented about equally over the three regions These findings could imply that region of residence is a confounder of the views that parents hold

Another potentially meaningful finding was that our subgroup-A (children who became deaf between 2 and 3) were under represented both in reference to pragmatic motives as well as "extended" pragmatic motives to choose for Sign language Though we cannot draw final conclusions given the small number of respondents, we do feel that this may be of interest The subgroup-A children (n = 7) were all over 10 years old,

generally were above average in spoken language skills and 4 out of seven were mainstreamed at the time of the interview Utterances on extended pragmatic concerns were supported by two subgroup-A respondents only Utterances on pragmatic motives to choose for Sign language were supported by 3 subgroup-A respondents Furthermore, three out of six cases that supported extended pragmatic concerns and all cases that upheld the bilingual thesis were the parents of a very young child ($\leq$ 5 years) These findings could imply that age and (perhaps as a confounder) success in oral-aural terms is a confounder of the views that parents hold

Conclusions

In spite of overwhelming emotions that parents endured around the time of diagnosis, it was found that our respondents were very much aware of the need for change and highly motivated to realize this Congruent with Scorgie, we found that parents exhibit a great capacity for transformation or change (Scorgie 1996, Reinders 2000) The most evident of this is the fact that parents come to accept the diagnosis and the permanency it implies, come to focus on their child's happiness rather than personal feelings of agony, focus on what is possible, universally choose for Sign language and succeed to turn away from the social prejudice of disability (Reinders 2000) Contrary to what one may be inclined to think based on what we discussed previously and based on what has been suggested in literature, parents did generally not express to have felt that their emotional suffering inhibited their ability to make sound decisions On the contrary, most parents were surprisingly assertive in their bearing towards their child (Mattson 1972, Philp 1982) Though parents confessed that it took "years" to adjust to the new situation fully - Gath found that 90% of parents of a child with Down syndrome still expressed grief 6 years after the child's birth (Gath 1977, Philp & Duckworth 1982) - their narratives disclosed that this did not necessarily interfere with their ability to respond swiftly nor adequately Eldik also reports that most parents succeed in adapting quickly to the new situation (Eldik 1998) Since parents could not navigate on common knowledge they needed to seek out knowledge actively, which most of them did Parents consulted a broad range of sources to undo their ignorance In general it appeared that parents exhibited a "problem oriented" strategy in which problems were identified and faced head-on rather than resigning in powerlessness We did not find evidence which supports the hypothesis of unresolved or persistent grieving (Sloman 1993, Meadow 1980, Hindley 1993), in the sense that the grief which parents did experience did not appear to interfere with information gathering nor did it yield paralysis or freeze, as has been suggested by Simons and others (Simons 1987) While this strategy may be explained in terms of coping with their own feelings of powerlessness, it seems preposterous to reduce it to such a strategy The main "problem" that parents identified and targeted in their search for answers was the threat of failing to realize communication and establish a satisfactory parent-child relationship

When parents consulted sources, they soon learned that it was hard to find encompassing information about deafness. The information that they found was often limited in scope. Information for example, never reached beyond childhood and adolescence. Furthermore, the broader dilemmas such as the tension between oral and manual instruction were often not included. Information was often institution-biased. Many parents were not even aware of educational alternatives. As such it was theorized that some parents might actually base their decisions on this narrow-scoped information. Some parents actually reached beyond the information provided by individual institutions. Yet this did not necessarily better the situation. Parents who succeeded to probe deeper only found themselves caught in the swamps of the method-controversy. As a result, parents felt abandoned by professionals since they failed to provide information that allowed parents to proceed.

In spite of the insufficiency of information, parents needed to decide on a communicative mode rather speedily. Somewhat surprisingly we found that almost all parents chose for Sign language and that most did so swiftly, often within weeks after the diagnosis was established. We suggested that several factors explain this finding. Firstly we found that the advice to engage in Sign language is rather unanimously in the Netherlands. Secondly, we suggested that Sign language is one of the few concrete things that parents can actually do in this stage, which supports them from a coping perspective. Thirdly, Sign language "fits" closely to the values that parents hold in this stage in time.

DISCUSSION

When we observe the early decisions parents made, the almost unanimous decision for Sign language stands out. With the exception of two cases, all respondents chose to communicate through Sign language and the decision to do so was made surprisingly speedy. Several factors explain this unanimous and speedy decision. Firstly the expert advice to do so was rather undivided. Secondly, and at least as importantly, the decision to proceed with Sign language yielded a "close-fit" with parents' attitude and values in this phase. As we have argued in chapter three, parents primary value was to facilitate communication, and through this establish a rather "normal" affective parent-child relationship. The demand for this was rather great, perhaps triggered by parents' sense that they had some catching-up to do. When parents researched the available options they soon discovered that Sign language was depicted as the best method to achieve this by far: Sign language simply was considered the most effective method to establish a relationship with one's deaf child. The fact that this decision implied an "offbeat" language did not seem to trouble parents much, which may be explained by what we said about the de-essentializing strategy that parents effectuated: the "special approach" of Sign language may have been perceived as an adequate answer to one of the problems located in the domain of the "what" of deafness. Its adequacy is explained by the fact that it facilitates what parents wanted in this phase: a rather normal experience of the "who" of the child.

Yet there are other aspects that explain the inferiority of an oral approach in this phase. Again this has to do with the values that parents held on the one hand and the way in which oralism and manualism are depicted on the other. As we argued, parents desired a "normal" experience of their child. More specifically, they desired a relational experience that is unobstructed by generic scripts on the "what" of their child. In this phase the most prominent generic script that they had to fence off, was the image they themselves held, an image encapsulated in the prejudiced "defective" narrative of deafness. This to some extent explains the aversion that many parents verbalized vis-à-vis the oral approach. Much more so than Sign language, the oral approach *visualizes* what the child cannot do, visualizes his or her "defectiveness". It seems much harder for parents to conceive of oralism as a "strategy" in the domain of the "what" of the handicap. If they choose for oralism exclusively they will, given the difficulties that a young deaf child experiences in learning this, become his or her teachers rather than parents. Rather than having a normal round of talks about how the soccer game went today, parents will be "working on" the child's language skills: "it is *ball* John, not *hall*". As such the "what" and the "who" of the child become rather intricately intertwined. Parents apparently resent such a "pedagogical relationship" in this early stage. It conflicts with the parental role they envisioned, but it also conflicts with the ideals they have vis-à-vis early childhood. Regarding this latter point, parents feel that young children should not be put into such a pedagogical environment.

This latter conviction is replenished with additional arguments in which literature and expert advice must have provided Essential ingredients are the suggestion that exposing young children to such an environment would result in psycho-emotional trauma On the one hand the pedagogical environment itself was depicted as culprit if children are not allowed to play and are cheated from a warm and normal family life, this will injure them On the other hand it was related to the fusing of the "what" and the "who" that we mentioned above Parents reasoned that if oralism is upheld at an early age, an age when the "who" of the child is in the midst of being shaped, the "who" of the child will inevitably be influenced by the negative connotations of the "defective what" expressed by the oral method An "injured self" would be the consequence of this, something parents clearly wanted to prevent Both hypotheses were encountered in literature and expert advice, which strengthened parents in their conviction Furthermore, the autobiographies of orally trained deaf adults were presented as empirical support for this case The role of autobiographies on how parents experience their child's disability, has also been pointed out by Isarin (Isarin 2002) Oralism was also perceived as a route that would inevitably delay language acquisition and as such would result in "language deprivation" Language deprivation in itself was also viewed as harmful to a deaf child Many studies deduce the theory of language deprivation from studies performed under adult deaf individuals, individuals who attended deaf institutes quite some time ago In line with Eyers critique on Spitz and Bowlby (Eyer 1996), it should be recognized however that while a lack of access to language may indeed be a key factor in explaining self-reported suffering as well as objective emotional disturbance in adult deaf populations, numerous other risk factors may confound the findings by these authors Discussing orphanage children for example, Eyer argues

> The infants lay in their beds all day long with nothing to do, had as many as fifty caretakers in their first eighteen months, and died of measles epidemic (Eyer 1996, 76)

It is crucial to note that all the arguments that we mentioned so far are rather pragmatic in origin and are not by nature encompassing or foundational Parents did not reject oralism on foundational moral grounds, but simply felt that it was an inadequate answer to the problems induced by their child's deafness in this phase Possible resultant problems in the future were countered by bilingual theory, with which some parents were familiar, almost all of whom resided in northern or western regions and many of whom were the parents of a very young child ($\leq$ 5 years) Most importantly, these arguments pertain to early childhood and the phase when language is lacking and child-identity and parent-child relationships still need to be shaped It is hence conceivable that a different perspective arises when these local factors change It is conceivable for example, that once a satisfactory parent-child relation is established parents will re-evaluate the role of oral language

Yet the narratives that we encountered in some of our respondents refute this Some of our parents utilized arguments that clearly went beyond pragmatism The DC-ID

narrative represents a rather encompassing and foundational perspective on deafness in which Sign language is conceived as the *only* justifiable preference Two separate directions could be distinguished Firstly, some of the pragmatic arguments mentioned before "solidified" or transgressed their local anchoring in aiming to facilitate well-being It was assumed that deaf children *only* have access to Sign language as primary language Subsequently it was postulated that man has a fundamental need for a mother language It was assumed that deaf people can *never* engage in symmetric relationships with hearing peers and subsequently argued that man has a fundamental right to symmetric relationships Parents of all regions expressed these arguments Yet we noted that parents of young children were over-represented in this context while subgroup-A respondents were underrepresented Secondly, in its most outspoken form DC-ID essentialized deafness as a cultural or existential trait As such its attributes, Sign language most prominently, become rather non-negotiable The central ingredients of this argument are existential and juridical in nature The central argument is existential deafness is not perceived as a "trait of the child" but something the child "is" and as such a deaf child has a "right" to Sign language and a vital minority community These excerpt were the exclusive responsibility of a minority of parents residing in the northern or western regions of the Netherlands Moreover all three parents paraphrased in this context were active political lobbyists for Sign language education

In either case, the use of foundational DC-ID arguments triggers our interest, since both its routes could co-explain the divergent paths that parents engaged in In particular adherence to the identity discourse seems to predestine parents towards a strong Sign language/Deaf culture orientation Yet the extended pragmatic arguments and the belief in the promises of bilingualism could as well In this context it is worthwhile to note three things Firstly, the DC-ID and bilingualism arguments are highly cognitive in structure, which makes it likely that they come into existence through expert advice The fact that we found adherence to both views to be rather common in parents who reside in western and northern regions is an interesting finding in this respect Secondly, the extended pragmatic arguments are in theory still sensitive to context, which could imply that parents may modify them as the context changes This is to say that once the child matures and become a "real-life benchmark" for the psycho-emotional concerns incorporated in this latter argument, parents may come to perceive things differently their child may either reinforce concern or disprove it Furthermore time may also illuminate previously unknown liabilities of Sign language and is likely to reveal the real potential of bilingualism From this perspective it was interesting to find that cases of very young children, who lack such a real-life benchmark, were over-represented while subgroup-A respondents were under-represented vis-a-vis extended pragmatic concerns The fact that subgroup-A respondents were underrepresented vis-a-vis pragmatic reasons to choose for Sign language may signify that these parents are far beyond such motives since most (5 out of 7) of these children were highly proficient in spoken language and many of them (4 out of 7) were mainstreamed This suggests that extended pragmatic concerns are still pragmatic rather than solidified since they are highly dependent on

local circumstance. Thirdly, if parents would come to change their view based on changed circumstances they would still have to deal with the most outspoken DC-ID arguments. As we notes, the Deaf-identity and Deaf-culture arguments are rather powerful and non-negotiable: it is unlikely that they can simply be cast aside. As such we anticipate that dealing with this discourse requires a significant tour de force.

In the next chapter we will further scrutinize parents' experience. Given what we discussed in this chapter we will probe for regional influence in terms of expert advice. We will analyze the impact of experience and local factors on how parents define their direction. Finally we will highlight how parents dealt with the essentialist DC-ID discourse.

CHAPTER 5 – THE EVOLUTION OF SELF-WILLED PARENTS

INTRODUCTION

In chapter four we provided some landmark conclusions regarding the early decisions that parents of deaf children must take, most importantly the decision for a communicative medium. We found that, in spite of intense emotional suffering directly around the diagnosis, parents were rather assertive in dealing with the problems that they encountered. Parents realized that deafness yields specific problems, most importantly the problem of communication, which need to be tackled swiftly. In spite of rather opaque and conflicting information, parents acted speedily as almost all chose for Sign language within only weeks after the diagnosis. We suggested that this unanimous decision was explained by a number of factors. One of the most crucial factors was that the discourse that parents encountered on Sign language yielded a "close fit" with the values they held at that time. Parents desperately wanted to instate a communicative means so to establish a satisfying parent-child relationship and Sign language seemed like the most efficient tool to realize this goal. Furthermore, parents valued their child's emotional well-being most highly and felt that oralism would injure their child for a wide range of reasons. Given the cognitive character of this latter argument, we suggested that counselors must have played a role in constructing it. Possible liabilities of the choice for Sign language in terms of its negative relation to spoken language acquisition were either considered irrelevant (parents were focused on present problems), unknown or were "invalidated" by bilingual theory. All in all it appeared that most parents chose for Sign language pragmatically: given the circumstances parents viewed Sign language as the preferable way to go. Yet we also noted that a few parents verbalized their choice for Sign language in rather encompassing and foundational terms, which we labeled Deaf Culture Identity Discourse (DC-ID). We noted that parents of younger children and parents residing in the northern and western regions of the Netherlands expressed this opinion most frequently.

Regarding the suggestion of the role of counselors and regional factors it seems that region-related expert advice - in the broadest definition of "advice" - must be at stake here. Though cultural differences cannot be excluded - the northern and western regions of the Netherlands are predominantly protestant while the southern regions are mostly catholic - it seems more likely that the regional factor is a confounder for school of attendance and the type of counseling received there. We recall that the Guyot school in the north and the Amman school in the west are both strongly Sign language orientated while the IvD in the south is famed for its oral program. This suggests that regional factors are an issue to consider and that we should focus on the impact of the school of attendance on how parents verbalize their motives. Others always play a role in decision-making (Adler 1988; Berger 1967). Edwards for example, articulates how adults operate within a hermeneutical circle aimed at finding consensus or "narrative continuity" about the truth of historical events (Edwards 1988; Gergen 1994). The self-narrative will thus make reference to social context, discourse, and conventions: it will have to embed itself

into this wider narratological context. Gergen argues that narratives are commonly arranged around "a point" with established value within the culture" (Gergen 1994). Darling states , for example, that "outside agencies supply the rationalizations...of our actions" (Darling 1983).

The experience of parents of deaf children is exceptional and interesting in this sense since the introduction of a deaf child into the lives of parents often rapidly leads to the forging of new social ties, which may constitute a new narratological context. Most Western countries have an established and elaborate social network to comfort a deaf child and his or her parents. By virtue of the institutionalization of this network in society no single parent can avoid it. Throughout the Netherlands a great many audiological centers are the gateway to this network. These centers often provide the earliest care. They also often introduce parents in Sign language classes and initiate contact with other parents of deaf children. In a later phase, these centers refer parents to a specialized institution that will provide education for years to come. We will refer to this new social network - formed by audiological centers, deaf school personnel, parents of other deaf children and deaf adults - as "deaf ecology". To use the term "ecology" suggests a social network that is rather unique, coherent and distinct from mainstream society, both in physical terms as well as moral or normative terms. Both of these possibilities are of interest and may have impact on how parents decide.

In normative terms we anticipate a rather unique and coherent perspective or "discourse" - Foucault speaks of discourse when one can detect regularities or consistencies between objects, utterances, concepts and thematic choices in a text (Huijer 1996) - on deafness within the newfound social environment. We deduce this through several channels. Firstly, through extrapolation from the experiences of parents of children with other disabilities, such as mental retardation (Reinders 2000). Secondly, the controversy surrounding these decisions is rather fierce as compared to the mainstream educational debate, which may lead to more outspoken as well as more detailed positions. Lampropoulou for example found that teachers of the deaf differ considerably in their view on educational inclusion as compared to those employed by regular schools (Lampropoulou 1997). Both issues may instate a discourse that is strong and organized yet rather peripheral in pedagogic terms. Thirdly, by reverse-reasoning: if deaf children have been segregated categorically, which they have, some idea which renders "the normal world" categorically unfit for them must underlie this fact. In the previous chapter we found tentative evidence of such a discourse in the form of DC-ID. Through a process of familiarizing, socializing and internalizing the potential impact of a unique deaf ecology discourse is rather large.

In physical terms deaf ecology represents the reality in which parents live. This ecology consists of relationships with teachers, other parents and still others such as deaf adults. Relations are an important medium of course for the abovementioned moral perspective. Yet it also provides the social or relational means to "influence" through

social control if individuals choose to dissent. It is therefore deemed interesting to provide not only a summary of the *content* of deaf ecology discourse, but to analyze its *structure* and social implementation as well. From here we can proceed to analyze if and how this structure is of influence on how parents decide for their deaf child.

Regarding the previously mentioned overrepresentation of parents of young children vis-à-vis DC-ID utterances we suggested that this might be explained in rather pragmatic terms. Parents of young children lack a real-life benchmark to measure the concerns expressed in DC-ID. These parents simply have no "evidence" to determine their child's language potential, emotional well-being, social skills, emotional resilience and so forth. Hence lacking an experience-based "model" parents are likely more in need for guidelines, a need in which DC-ID provides. They also lack experience in the sense that they have not experienced first-hand if the promises of bilingualism actually materialize. This could be argued to imply that experience is a crucial factor to consider. It may be that as the child matures and claims its own identity and as parents become more experienced and knowledgeable, parents change their views. One could suggest for example that the process of de-essentializing that we described vis-à-vis the negative narrative on deafness may eventually also be applied to the DC-ID. It seems likely however that if this occurs, it will only be after several years rather than months of experience. Normal children start their language development from the age of about 12-18 months and it is not until the age of 5 or so that they produce full and well-built sentences (Goorhuis 1978). It seems likely that if one chooses for a specific language path in "language-disabled" deaf children, one will not reflect on this choice until the goals of this process have been completed satisfactory. Furthermore, most children do not initiate their true educational career - hence excluding kindergarten - until the age of six. This implies that parents may come to refocus at that time since the objectives of the school years are different from those of early childhood. As we argued in chapter four, the choice for Sign language was in part explained because it yielded a "close-fit" with parental values at *that* time. Yet in time these values may change. There is good reason to assume that the parental perspective will change, even without considering the above-mentioned factors. A change in values and goals with increasing age of a child is rather common to parenting, an issue that we will discuss in more depth in chapter seven. Parental values do not represent a "stable set" but are rather variable over time, a fact which leads Hoff-Ginsberg to speak of a "moving target" (Hoff-Ginsberg 1995). While parenting young children is likely to focus on affective or "gardening" values, a pedagogic environment that aims to safeguard "guardian" values such as self-reliance or autonomy will increasingly surround the maturing child.

Examples of Ruddick's categories (Ruddick 1979)

Gardener

- Child as vulnerable and dependent
- Care orientated
- Importance of parent-child relationship

- Indulgence to child's desires
- Child as extension of parents

Guardian
- Child as independent individual
- Autonomy orientated
- Importance of an "open future"

The object of guardianship is strongly orientated at the child him or herself, perceives of the child in terms of a separate individual early on More strongly so than the gardening view, guardianship separates parent and child as two autonomous actors in the parent-child relationship (Blustein 1979) This appears to yield a juridical discourse composed of several actors with well-defined and circumscribed rights and interests (Mnookin 1979) Its mission states that parents primarily ought to respect and protect their young's well-being (van den Boer 1997) and that their aim should not be "personal honor or glory, but orientated at the best-interest of the child, who has to be raised to autonomy" (Jacobs 1993b - translation ccw) Far from categorically denying parents the right to expose a child to their specific preferences, this view does claim that what parents should aim for is primarily an "open future" autonomy is perceived as related to the number of options which an individual has to his or her disposal when competent to make decisions (Feinberg 1980, Archard 1993) Ruddick states for example, that a child's guardian needs "to see that he is properly trained and educated and that he has the opportunity to learn a trade, occupation or profession" (Ruddick 1979)

Indeed Ruddick's description of gardener values fits closely to what we described in the previous chapter parents were highly focused on the *quality* of the parent-child relationship and aimed to optimize their child's emotional well-being in the present time Yet Larson states that the challenge for parents of a disabled child is ultimately strongly located in the future, which may be argued to be actually true for all parents (Larson 1998) While the gardening values of early childhood can be fulfilled rather successfully through Sign language, the outlook of guardian values such as an "open future" remain uncertain In chapter three we suggested that parents dealt with this uncertainty by "shoving aside" the future and focusing on the direct present instead In chapter four we found that, after time, this perspective changed somewhat as parents became more aware of the limitations that deafness instates Parents progressively separated the "what" of the handicap and its limitations from the "who" of their affective child This seemed to assist them in developing a "problem orientated" attitude in which they could target the problems instituted by deafness without becoming overwhelmed by emotions of non-acceptance In a way the decision for Sign language was the resultant of this It was a problem-orientated answer for the prime problem of early childhood, namely the lack of communication Yet it still more or less ignored the problems that awaited the child later in life Given what we discussed here, we would expect parents to at least position themselves vis-a-vis the future problems of their child as the child matures This does not automatically imply that they will become more guardian-orientated like parents of non-

disabled children do. Yet if they do not, we would at least expect them to actively present a discourse that legitimizes such a decision since it clearly moves away from our dominant child-rearing discourse. In sum we conclude that the next factors require further scrutiny:

Factors under scrutiny in this chapter

- Regional factors
    - Analysis of normative discourse
    - Analysis of impact of social environment
- Developmental stage child
    - Older child provides a "real-life" benchmark for the validity of concerns and expectations
    - Older child as measure of promises of bilingualism
- Developmental stage parents
    - Experience increases (see "developmental stage child")
    - Knowledge increases
    - Changing values towards guardianship
    - Refocus likely to occur only after initial goals (communication) are reached

We will begin by describing the changing social environment. Next we will outline the normative character of the discourse that parents encountered in deaf ecology and describe the role of the social structure of that environment. Finally we will analyze if and how the parental perspective changed in time, relate possible changes to the developmental stage of both parents and child and discuss what these possible changes meant for the relation between parents and deaf ecology. To discuss this latter topic we need to separate "experienced" from "inexperienced" parents. Given what we discussed above, we felt that an "experienced" parent must be the parent of a child that is well settled in grade school. We chose the age of 8 as a criterion here. We did not a priori exclude excerpts of "inexperienced" parents however, because the potential relevance of parental experience arose after the first draft of this text was completed and because exclusion of the experiences of inexperienced parents would as such imply a missed opportunity to allow the empirical material to illustrate this relevance. All excerpts by parents who did not fit this criterion will be printed in bold and the age of the child will be provided.

THE NEW SOCIAL ENVIRONMENT

General issues

In chapter four we described that parents felt abandoned by professionals in solving the problems of deafness. It appeared that this feeling was intensified by the lack of meaningful support and input by significant others, something which has been described in illness experiences in general (Eldik 1998; Wever 1997). Many parents found that relationship with friends and family became more distant in the aftermath of the diagnosis. While the need for support was quite large indeed, especially in the early days of the experience, parents said that their familiar social environment failed to deliver in this context with the exception of a few good friends.

> *M: They [friends] come here and such...but you don't have that many friends anymore you know?[.] You still have some friends but they are the good friends, those to which you can appeal in the middle of the night if needed, but the regular friends are gone you could say. It is a select group that remains (C16b)*

It may be that the isolation is "unwanted" in the sense that it is the result of a lack of "initiative" by others, who do not know how to deal with the "tragedy" of deafness. Likewise, it may be the result of self-isolation, in an attempt to cope with a non-understanding environment. Both suggestions were touched upon in the previous chapter (C1, C7a).

> *M: If they [friends, colleagues] can they will avoid you Because, how do you handle someone which such a problem? You do get fewer friends because of it you know? (CO3)*

> *F: Our family did not know how to deal..*
> *M: And people around us started to avoid us, because they did not know how to deal. (C4ab)*

While these explanations place the blame with family and friends, one can also reason that the introduction of a disabled child into the lives of parents opens the door to a rather unique experience that is so "marginal" from a cultural perspective that it inevitably isolates them to some degree. In the context of physical disability it has been argued that the content of dialogue becomes incompatible so to say: while friends continue on their route of the healthy - talking about work, career, children and so on - the person with a disability becomes engaged in a different discourse (Wever 1997). This development may cause friends unease. Similarly, it is likely to cause parents unease as they may feel that they are not being "heard" and their situation is perpetually being judged from the "wrong" perspective. Parents find it hard to communicate "in the right tone" with inexperienced others about their child, or phrased differently: parents experience

difficulty in breaking through the disability image of deafness which is so tenacious to inexperienced others. Indeed, we suggested in the previous chapter that parents too are stigmatized (courtesy stigma), which limits their conversation range to the rules set by the dominant narrative on deafness. Perceived as such it seems that neither party is to blame.

Yet parents will have to find a way to deal with this. As has been described by people with a physical disability, humor is one way to avert the ever-threatening pitiable narrative and can "break the ice" so to say (Wever 1997; Spaink 1993):

> *F: In the beginning we used to make jokes about it, if you do not do that you will distance yourself from others, from friends. (C14b)*

Yet it seems that the confusion of tongues is not the result of courtesy stigma alone. The deaf experience also appears to induce a general change in parents, in the way they stand in life so to say (Reinders 2000).

> *I. How do you explain that [retreat of friends]?*
> *M: You don't really feel like it anymore You know, when I go to a party and listen to the nonsense chitchat I think 'what am I doing here?' I have grown out of that a little. (C16b).*

> *M: Your mind is just not set on when it is Christmas or Easter. You're always behind, because you are thinking of other things. [...] Preferably they avoid you Because what do you talk about with someone with such problems? You end up with fewer friends. (CO3)*

Yet, more pragmatic explanations apply as well. Raising a deaf child consumes a lot of time, thereby limiting time to socialize with friends and family (Philp 1982; Harrison 1977; Burton 1975).

> *M: Yes, it was a big change. You do everything for your child, everything he or she needs at the time and you take ample time for it. She is number one in the family, she gets the time she demands. [...] You just need more time than you do with the other kids. (C1a)*

Parents also revealed that even if family and friends did not experience the hurdles described above, failure to communicate with their child could cause them to stay away. Many parents revealed that family and friends had difficulty in communicating with their deaf child:

> *M: You notice that especially in the family that one person has no difficulty at all communicating with her while another, you just notice that another has more difficulty...to say something to her or to appeal to her. [...] At a certain point they are able to understand some but not...I often had to help out.*
> *I: You helped out?*
> *M: Yes*
> *I: Translate?*

M: Yes. (C1a)

It thus appeared that the level of support found in family and friends was co-dependent on the degree in which communication with the child was maintained or established. Sign language was crucial in this respect. Some parents were energetically involving friends, family and neighbors. They did so for example by involving them in Sign courses and by actively inviting them into their homes.

M: I gave 'illegal' Sign courses here at home Sometimes there would be 40 people you know. I would do it four nights with 12 people each time, I could not handle more.
I: Who would come?
M: All kinds of people, family, neighbors, friends, teachers...(C12ab)

While this effort did commonly lead to some basic Sign language skills, thereby eliminating one obstacle, parents did report that it was rare that family and friends reached beyond a basic level of fluency.

I: How about grandparents Did they learn to sign? Did they take a Sign course?
F: Yes a little.
M: But from us.
F: No, not through a course. (C2b)

F: Her teacher attended a Sign course and her grandparents all did as well. But they rarely reach beyond what I call kindergarten level. They just miss routine. (C9a)

M: Well, in the beginning it was very hard indeed. [...] My father and mother both tried, but things are hard. They still try to sign, but it is not optimal (C15)

I: Are there people in the family who learned Sign language?
M: Eh, well not really. I gave the Sign CD-ROMs to my father and, well, he does something with it. He tries to get into it. He can get along with him [deaf son] a little and, eh, I enjoy that. My mother does very little. (C8b)

I: What about grandparents, uncles and aunts? How do they communicate with her?
M: Well, that is rather limited, the communication I function as translator. (C10ab)

It appeared that even when actively involved, friends and family lacked tenacity in this sense.

M: Now they [family, friends] are signing less and less. In the beginning it was really touching to see how everyone was doing his or her best. (C12ab)

F. In the beginning they tried to master Sign language The basics anyway, but after a few months you noticed that they had forgotten what they had learned. (C14b)

In spite of the lack of Sign language proficiency, parents did not always judge communication with friends and family as insufficient.

> *M: My mother tried sign, but it did not really work out. When she was still young she communicated with her grandparents with signals, pointing and such. But it was pretty good She got what she needed and they understood one and other But now that she is older it goes better all the time She speaks and my parents have developed a certain mime.*
> *F: She is happy, they understand one and other and she is welcome, and that is very important. (C7a)*

> *M: Oh, the loving relation is very much present and you notice that. [...] She goes there [to grandparents] without any problem for a few days That is no problem. But full discussions are more difficult. Logical. (C10ab)*

Some parents appeared not to blame family members for their inadequate Sign language skills since they felt that one cannot reasonably expect people to be proficient in Sign language if one does not have to deal with a deaf child on a day-to-day basis. This position had both a practical as well as a moral implication. From a practical point of view, some parents seemed to feel that only a day-to-day involvement with a deaf child *can* produce Sign language proficiency.

> *M. You have to be involved constantly with a deaf person, the whole day, if you want to maintain Sign language, keep doing it. (C14b)*

> *F· Our parents? No. I think they are not able to become very good at it [Sign]. And they see her too little to reach proficiency. (CO4b)*

From a moral perspective, some parents appeared to feel that one cannot reasonably expect the kind of intensive investments required to generate Sign proficiency from people who have no daily relation with a deaf child:

> *M· Like with sign, you are allowed to take someone with you to a Sign language course, but you don't want to impose that you know, like 'you must learn Sign language'. (C8b)*

Yet not all parents were as understanding of the failure of family and friends to establish a fluent mode of communication with their child:

> *I· How proficient are grandparents in sign?*
> *M: Bad.*
> *I. How does that make you feel?*
> *M: Terrible, that no one takes the time to...yes terrible They say that they cannot but I could not Sign at first either, right? Yes, I really regret that. And it is not like grandparents visit once every two years, they visit almost daily.[...]*
> *I· How do you explain it?*

M Laziness Well they are too old too, but if I think about it a sort of laziness I think Look if I do it they think it is the logical thing to do, but if they don't, yes I don t know, it is a little strange (C16b)

The retreat of family and old friends was accompanied by the forging of new relations in the direct social environment of the child's deaf school Other parents were an important ingredient of this new environment We would hesitate however to label these new social ties as "friendships" The general trend was that parents did not speak about "friends" when alluding to these new social ties, but rather used a more distancing vocabulary

I Did you make a lot of friends with other parents of deaf children over the years?
M No, not really (C1a)

Though some did speak about friends (C15), the most common designation was "other parents", "the parent of ", "the mother of ", "the father of " or simply the family name of the person in question This may be an expression of the fact that parents did not choose these social ties, but rather formed them out of "shared misfortune" so to say

Several factors explain the emergence of new relationships in deaf ecology Firstly, the practical factor of time parents simply spend a relatively large proportion of their time in the deaf school environment

I Did you meet up with other parents?
F Yes, you meet other parents automatically she attended kindergarten for deaf children and you meet other parents there (C2b)

Secondly, the forging of ties within the deaf school environment seemed to fulfill in a need for knowledge, support and understanding, the kind that parents missed in their inner circle Quite a few parents said that they found support in their new group of friends through shared-experience, something that has been addressed abundantly in the context of illness experiences in general (Wever 1997) The narrative discontinuity that we discussed above does not occur in the interaction with peers

F We got a whole new group of friends over time You have different friends, the old ones too but if this did not occur we would have had different friends We got a different kind of friends Not that we see each other every day you know, but you have a common topic though you do not talk about that only but it does connect you (C15)

M Well yes the people we met at Sign courses, people with the same problems as us really
F You do not expect that there are so many people We did not expect that [ ] You know about those institutes but you just drive by When you enter the building you know that you are not alone (C8b)

Yet, the new social environment was shaped by considerably more than peer-parents alone. Deaf school teachers and counselors, deafness experts and deaf adults were just as much a part of this environment.

Specific issues, cases and controls

Though we cannot support this empirically, it was our general impression that the impact of the new social environment was larger for parents residing in northern and western regions, though this may also be co-explained by the fact that mainstreaming and attendance of a school for the hard of hearing was more common in the southern region. Still one parent whose child attended IvD and who previously resided in the western Netherlands complained about the "lack of togetherness" at the former institute (CO3). Furthermore it is noted that politically active parents were more common in northern and western regions as compared to the southern provinces.

Conclusions

Having a deaf child often leads to a change in social environment. Old friends and family retreat to some extent. A lack of time to socialize with old friends is a likely factor here. Yet parents of children with a disability have been reported to develop a different worldview. Our material shows this to be valid for parents of deaf children as well. This may provide a more fundamental explanation for the finding that parents grow apart from their inner circle. We also found that communication difficulties have negative impact on friends and family. Parents revealed that while some friends and family members made initial efforts to master Sign language, most failed to achieve a level of proficiency needed to communicate with their deaf child. While some parents were rather understanding of this, others renounced it. The retreat of old friends and family was accompanied by a steady increase of the social significance of others encountered in the direct environment of deaf school. Parents encountered other parents and found these social ties valuable at least from the perspective of "shared misfortune". Yet others in the deaf school environment also contributed to parents' new social circle. Teachers, social workers and other deaf school personnel as well as some deaf adults came to function as a sounding board in an increasingly fashion. The degree in which the social world around deaf schools impacts parents' social life, may be dependent on school of attendance. Parents in the southeastern part of the Netherlands appeared to have been less absorbed by deaf ecology. It may be that the dominant de-centralized educational setting was an issue here. A minority of our respondents from southeastern provinces attended a classical deaf institute: 2 children attended IvD while 4 attended a school for the hard of hearing and 4 were mainstreamed. In the northern provinces the pattern was distinctively different: 6 children attended the Guyot Institute while only 2 were mainstreamed.

DEAF ECOLOGY AND ITS DISCURSIVE DISPOSITION

Introduction

In chapter four we described the motives that explained why parents chose for Sign language almost unanimously. One of the central reasons was suggested to be that the discourse surrounding Sign language yields a close "fit" to the values that parents hold in this stage. Parents longed for a satisfying relationship with their child, valued emotional well-being most highly and held an implicit yet specific view on the ideal childhood environment, and concluded, based on intuition as well as the information they received, that Sign language best safeguarded these values. In addition to these pragmatic arguments, we encountered solidified pragmatic beliefs as well as utterances on Deaf culture and deaf identity, which we have labeled DC-ID. Regarding the latter arguments, we suggested that region and experience were factors since we found that parents residing in the northern and western regions and parents of smaller children were most likely to engage in DC-ID arguments. The two may actually reinforce each other since we argued that parents of young children might be more sensitive to expert guidelines, given that parents lack knowledge, experience and a "real life benchmark" in this phase. Yet as we argued in the introduction of this chapter, the suggestion that social environment has a distinct impact on how people think and decide is rather unremarkable in itself and, as we have shown in the previous section, the interesting thing about the experience of parents of deaf children is that distinct changes actually do take place regarding the composition of their social environment. Many parents lose contact with their intimate social environment while the social environment constituted around deaf schools becomes of increasing importance. Furthermore we touched upon the possibility that this new social environment goes hand in hand with a rather unique and powerful discourse vis-à-vis deafness. DC-ID may be said to be such a discourse, since it contains arguments that appear to set deaf children in a different order. Still the possibility remains that DC-ID arguments are not encompassing after all but rather eventuate "strategically" from the conviction that Sign language is the only feasible mode of communication for young deaf children, given the centrality of gardener values in this developmental stage. If however DC-ID represents an encompassing and foundational narrative that categorically sets the deaf aside in a unique order, one would expect that the content of DC-ID will *not* change over time, maturity or in response to context. If such would be the case, it would likely be illuminated in terms of specific issues that arise in the context of the older school-going deaf child. Once Sign language is satisfactory instated, how much are deaf children challenged academically and in oral-aural terms? Is mainstreaming ever considered a valuable option? Are socio-emotional values replenished by future-orientated guardian values such as autonomy and an "open future"? What future perspectives are held and aimed for, both in societal as well as in socio-cultural terms? In this section we will investigate the content of deaf ecology discourse in the context of the older school-going deaf child.

The secluded "ideal" world

It appeared that deaf ecology upheld its view on the "ideal world" for deaf children well beyond the early childhood years. One could argue that deaf schools ought to ultimately aim to make itself superfluous as children mature to become competent citizens As Fromm states about regular education

> The more the student learns, the less wide is the gap between him and the teacher He becomes more and more like the teacher himself In other words, the authority relationship tends to dissolve itself But when the superiority serves as a basis for exploitation, the distance becomes intensified through its long duration (Fromm 1994, 163)

Yet deaf schools did not appear to strive towards such dissolution This was particularly obvious when parents considered educational mainstreaming. While the IvD did appear to cautiously promote mainstreaming, a different attitude was encountered at all other schools for the deaf. Mainstreaming was limited to a once-a-week program for "social integration" and it looked as if this preference represented a rather structural attitude, meaning that it was independent of an individual child's developmental stage or capacity Thus, transferring a deaf child to a regular school was rejected rather categorically

Much like what we described in the previous chapter, arguments referring the socio-emotional well-being of deaf children were paramount here Enrolling a deaf child in regular education was perceived as "too challenging" and as such deemed harmful. To get along in such a setting deaf children would have to perform an overly demanding task, which would injure them emotionally

> *M So when we considered mainstreaming her, well they [deaf school staff-ccw] were moderately cooperative but there was a certain pressure against it till the very end like "we are worried about her emotional development cognitively she can handle it but her emotional development and all" (C10ab)*

> *M The teacher told us that they felt things were going well and that he should go there [regular school], because he was ready for it But, social and emotional they came up with this lengthy story (C5a)*

Mainstreaming a child into normal school was feared to induce an "injured self" or a negative "self-concept", through the stigmatizing experience of being different but also through the experience of trailing behind in the educational and social process

Yet when does a "healthy" demanding task become a harmful "overly" demanding task? Some parents appeared to assume that different standards apply for deaf children in this context since they "have a tough day as it is".

M: Like: those kids, they have to try so hard already as it is. [...] They say that you will over-feed them, making them over-strung Children become over-strung from over-demanding parents. They have such a tough day as it is. You should just let them be. (CO1)

This notion of a rather generic form of "specialness" and a corresponding strong need to protect was rather wide spread, thus not limited to the things that deaf children overtly have difficulty doing, i.e. mastering spoken language and engaging socially with hearing peers. As such it appeared that the opposition against mainstreaming was symptomatic of a broader and more generic "low-challenging philosophy". Not only were children not challenged to speak, they were under-challenged in a rather global and encompassing sense, something that has also been addressed by Knoors who speaks of the "isolation, driven by the idea that everything is special about deaf children" (Knoors 1995).

I: What do you think the explanation is?
M: We have the idea that they [teachers] assume that that is just the way it is with deaf children. (C15)

M: They [signing deaf school personnel] told us that you have to choose for the cognitive or the social-emotional really. (C11)

The "infirmary model", which seeks to provide a safe and comfortable place foremost, was omnipresent. A low challenging environment was upheld and much attention was directed at social and emotional skills rather than achievement, be it in terms of spoken language acquisition or academic performance.

I: Can you describe the situation at deaf school?
M: Well, it is very social and all.
I: How do you explain that?
F: There simply is no progress. (C5a)

The one-sided social-emotional orientation of deaf ecology was further highlighted by the apparent lack of an educational plan that incorporates explicit objectives and regular evaluation, an issue that has been raised and criticized by Knoors as well (Knoors 2000). While the quality of an educational plan can also be measured in terms of a process-evaluation, it was the lack of an output or "harvest-evaluation" that parents criticized most fiercely.

M: But also not like "now he is this far, he can reach that level and we are going to do that through this trajectory" or something like that. (C11)

M: I wrote in his [school] notebook, like I want to know how he is proceeding with his speech training. I got a small note in return stating: at the end of the year we will report extensively and "all will be fine". (C14b)

F. They just shuffle on. There are no objectives at all. [...] We once asked: tell us, with what luggage will she leave this school? The only reply was "she graduates at age 13". But is that comparable with the minimum grade school level? They cannot answer that question That makes me think. come on! (C15)

M: Because a S.E. school, a special education school, has no final objectives. Everyone can just do as they please in class (CO1)

The lack of an educational plan was highlighted even more since most parents also had normal hearing children, so they could compare. Furthermore, many deaf children also attended hearing school one day per week, which allowed further comparison. It appeared that this comparison was unfavorable. The (implicit) output demand of deaf schools was far below what parents encountered at hearing schools.

F: To give you an example: at hearing school he was doing math 5 hours per week
M: Every week.
F: At [sign oriented] deaf school they did math 2 hours per week, but explicitly as deaf children Six children in a row and the teacher explaining things. Three would pay attention, two others were staring out the window because they had seen something. So they missed it. So the teacher would have to repeat. So effectively what they covered in two hours equates 30 minutes in hearing school. (C5a)

Deaf schools thus appeared preoccupied with how the child was doing socio-emotionally in the present mostly, thereby disregarding a developmental approach in which achievement standards can be set.

M: We had a meeting with the school staff about him. It was all wonderful, the reporting that they had made. Yes, he gets along well in the group, this is fine, that is fine. And we felt like, it is not fine at all! His reading is not fine at all. [...]
F: It was "all fine". We were in and out in three minutes We thought is was shocking that that team with a psychologist, the school director, a teacher and another scientist talked about him and what was the result? It was "all fine". (C11)

F: There is no explicit plan as far as we know. Do you understand? Cognitive subjects ..you can verify in theory, in an educational plan. The objectives that have to be reached by grade. I do not know anything so explicit in terms of social functioning. (C11)

In sum, deaf school personnel continued to view deaf children in terms of their socio-emotional well-being primarily. This resulted in a persisting low-challenging "infirmary" philosophy and explained why mainstreaming was discouraged and why deaf schools lacked an explicit educational plan.

Acceptance & the Good parent argument

Next to a persisting low-challenging philosophy we encountered a second powerful ingredient in deaf ecology discourse. Yet contrary to the former issue, this ingredient focused strongly on parents themselves as it targeted the topic of "acceptance". We discussed this topic briefly in chapter four vis-à-vis parents' early experiences with counselors, yet it seemed that this topic continued to color deaf ecology discourse and even gained in strength.

Acceptance can be viewed in a variety of ways, which we will discuss at length in chapter seven. Firstly, it may refer to psychological coping: acceptance in this sense equates a "healthy" coping process. In chapter three and four we suggested that we found no evidence for "denial" or "resigned" coping. Secondly, acceptance may refer to the pedagogic value of unconditional love: Good parents should love their children *regardless* of possible handicaps. In chapter four we suggested that parents indeed did succeed to form an authentic relationship with their child, unobstructed by feelings of defectiveness or pity. In spite of this, many parents did continue to dislike the limitations that deafness raises for their children. This may however be depicted as a proof of conditionality. Indeed we suggested that some parents were confused over the potential tension between their love for their child and their resentment of the limitations due to deafness. Indeed it appeared that deaf ecology discourse *exploited* this intrinsic ambiguity. When parents questioned the ideal world as prescribed by deaf ecology, "non-acceptance" was a frequent indictment.

> *M: We did not accept that our child is deaf, because we kept fighting to some extent for some input of the hearing world.*
> *F: Yes*
> *I: So accepting that your child is deaf implies that?*
> *M That you immerse her in the Deaf world. That she attends Deaf clubs. That she is not mainstreamed. That she uses Sign language and not Total Communication. That is acceptance according to the Deaf world. (C7a)*

> *F. I think that as soon as you deviate from the institute by saying "I want to mainstream my child" that...*
> *M: You do not accept deafness*
> *F Indeed, acceptation...it is so simply said: you must accept deafness. Well, we do (C9a)*

According to deaf ecology parents who insists on spoken language seemingly do not find their child good enough as he or she is. Trying to teach a deaf child to speak or aiming for a life in hearing society was rendered as a sign of inadequacy: of not finding one's child good enough, which is incompatible with the demands of good parenthood (Isarin 2002).

M: Their attitude was, a deaf person is not an inferior human being and you should therefore accept him, with his Sign language and that is fine, you should leave it that way...(C15)

If deafness is essentialized as an "identity-trait" and if Sign language and Deaf culture are defined as the hallmarks of that identity, aiming for oral-aural skills and mainstreaming become rather synonymous to intolerance. Indeed, deaf ecology continued to expand the concept of acceptance beyond its psychological roots to transform it into an existential narrative of identity and culture as we have previously seen in the discussion of DC-ID.

M: I know a parent couple, they have two congenitally deaf children. I met them rather shortly after my son became deaf, just to talk, like "what does it mean for you?". They made some bold statements like: "if our son could suddenly hear again, he would not be our son any longer". (C12ab)

As also described by Goffman, the discourse encountered in deaf ecology spoke in terms of "natural" socio-cultural "belonging" (Goffman 1963).

M: You had to accept that your child was deaf. And that implied that he belonged in the Deaf world (C7a).

M. They [Deaf adults] told us that we had to accept him the way he is. Well we did that a long time ago. They said that he belonged "to our [Deaf] culture". (C14b)

M: Deafness is a certain culture that we're not allowed to keep away from him
F: We were not allowed to take his Deaf culture away, they would say.
I: Is that what was conveyed to you?
M: Well, not by the school.
F: Not so much the school They are not allowed to say such things I think. [...] But there are a lot of deaf people and hearing parents of deaf children who do say that. (C14b)

By defining identity and socio-cultural belonging in terms of "Deaf culture", the specific attributes or assumed attributes of that culture are apparently adopted as morally imperative. Therefore an unyielding and fixed definition of Deaf culture becomes compulsory. Not withstanding the fact that the deaf represent a rather heterogeneous group of people, as we discussed in chapter one, the assumption is made that the Deaf community *does* exist homogeneously and is characterized by the fact that they do not speak and do not want to speak. As a result Deafness and speech were perceived as morally irreconcilable entities.

M: If you wanted speech they would say. "but he is a deaf child, just let him sign pleasantly, just let him be deaf, he just belongs to that...you should accept that he is deaf". (C14b)

> *M: There was a deaf man there [camp for deaf children-ccw] who used Sign language. He said like, a deaf without Sign is not a real deaf person We could not believe what we heard! (C15)*

Furthermore the assumption was made that the deaf exclusively socialize within their "native" group and have no desire to move beyond that: Deaf culture was characterized as rather isolated from the hearing world and it was assumed that this isolation represents a positive choice: that its members value or even cherish this isolation. Not wanting to speak and cherishing isolation may be depicted as the "militant attitude" that Goffman believes to be common in some stigmatized groups (Goffman 1963). Since the deaf child is portrayed as a "native member" of Deaf culture, mainstreaming becomes a morally questioning pursuit.

> *F. It is so odd that they draw such a hard line like· your child attends a signing deaf school and communicates in Sign language and thát is the Deaf world. [...](C9a)*

Evidently, the DC-ID argument is closely related to minority debates. Indeed, three parents (two of which of younger children) drew parallels to the situation of oppressed cultural or ethnic minorities.

> *F: But that is logical [that deaf adults are often bitter-ccw]. In that sense it is just like Eastern Europe so to say. The oppression of ones own identity, one does not experience that lightly. It is plain awful. (C13)*

> *M It is the same as Michael Jackson, he is dark from skin but wants to be part of the white population. White people may like that, but dark people find it sort of a rejection. They feel it is a rejection that Michael Jackson does not want to be part of them. (C14b)*

As we argued in chapter four, the DC-ID discourse relied on the "evidence" provided by the experience of deaf adults. Many parents alluded to this experience, which seems to suggest that it is a story that is told abundantly. While we discussed the experience of deaf adults in terms of the futility and damaging effect of oral-aural training, two additional implications were found. Firstly, as we have shown above, Deaf adults were perceived as live proof of the validity of the DC-ID argument. Secondly, the narratives by deaf adults were perceived as a warning of non-compliance: if parents did *not* comply with the demands of DC-ID they would risk condemnation by their child once grown up.

Ingredients of the Deaf adults' narrative

- Live proof of the futility of spoken language education
- Live proof of the emotional damaging impact of oral demands
- Live proof of the validity of the Deaf identity argument
- Threat to parents who ignore these issues

Many parents sensed the bitterness that deaf adults expressed over their past. Parents appeared to project these negative emotions onto their own situation and seemed to fear

that they could become the target of their child's anger if they did not comply with the demands of DC-ID.

> *M: I heard from deaf people how they experienced their past. In particular the negative experiences of having to talk all the time, not being allowed to sign...I think that was not good, that it had to be oral and eh, yes it has really affected them emotionally (CO6b)*

> *F. We heard from adult deaf people whom we met at courses and meetings. They had considerable aversion regarding the way the oral method was used in the past. That they were forbidden to sign So we concluded: we should not do that, the oral route. (CO4b)*

> *F. We attended several meetings...Representatives of Deaf culture would be present They were against everything really. [...] Like "us against the rest of the world". (C2b)*

In sum we found that deaf ecology discourse continued to stress "acceptance" in reference to the popular value of unconditional love and as such profited from the intrinsic ambiguity that this concept bears. Parents who questioned the "ideal world" as prescribed by deaf ecology were portrayed as "non-accepting", which conflicts with the demands of good parenthood. Furthermore we found that DC-ID continued to be of influence. Deafness was depicted as an identity-trait and Sign language and Deaf culture were defined as the hallmarks of that identity. As such parents who questioned the ideal world as depicted by deaf ecology were portrayed as "intolerant" parents much similar to the use of intolerance in the context of minorities. The narratives of Deaf adults were perceived both as proof of the identity-claim as well as a threat towards non-compliance with the DC-ID demands.

Choices of adherence

From what we have described so far it appears that deaf ecology positions its views in a dichotomous moral landscape. While "empirical" child-centered arguments were raised in the form of the suggestion that spoken language and mainstreaming would lead to emotional injury, the previous section showed how deaf ecology moved beyond the deaf child and homed-in on parents moral self-image as "good parents" (acceptance) and "good citizens" (tolerance). The framing of decisions within such a moral environment implies that "wrong" decisions are not legitimized through empirical evidence and pragmatic reasoning but through moral stereotyping. Basically two kinds of parents exist in this moral cosmos: "good parents" and "bad parents". As such it is not surprising that we found that choices were cast as choices of adherence really, demanding "either confirmation or rejection" (Reinders 2000).

> *F: There are a lot of parents who advocate it you know, if you listen at Guyot and hear parents speak about it, a lot of parents adhere to it. (C6)*

Non-adherence was reproved. Parents who considered mainstreaming for example, indeed experienced this

> *M I got the feeling from parents with whom we had reasonable contact that they thought "what are you doing to your child?" A dissident really*
> *I How is that?*
> *M Well why Like "how dare you put her in the hearing world all by herself and release her from that protective Deaf world, deaf friends, where she can have and develop her own identity " (CO7)*

> *F I don't think they would stimulate it [mainstreaming-ccw] They will never spontaneously say like "she can handle it, go ahead and try"[ ] I think if we would decide to mainstream her, we would taste some serious restraint (CO4b)*

> *F We encountered that strongly yes [dichotomy between Deaf world and hearing world - ccw] It was a Deaf world with deaf schools and Sign language (CO5b)*

The choice for spoken language was cast in a similar frame.

> *M But at the school they seemed to perceive speech as some sort of, how should I say it, a bit of a disgrace Like you should not aim to bring a deaf child to speech and if you do, you are doing wrong since they have to sign (C14b)*

> *F They [FODOK] disapproved of parents who did not use Sign language enough [ ] So you notice through the disapproval how they think about things (C9a)*

Parents who "adhered" on the other hand seemed to attain high status in deaf ecology:

> *F They [strongly DC-ID orientated parents - ccw] clearly have something to say Everyone will stand around them and listen That makes you think Oh my God! (C7a)*

Sometimes parents were also presented the issue of emotional well-being as "principal" in nature, either choosing for or against socio-emotional development.

> *M We were told that you either chose for cognition or for socio-emotional development and I thought, that is not how it is, that is not what I chose for! (C11)*

When transferring her child from a signing to an oral school one mother reported that she was called several times by an executive of the signing school:

> *M She [deaf education executive-ccw] called us several times asking me if I realized what I was doing We were put under pressure quite a lot [ ] We were blamed for emotional neglect We were going to encounter huge psychological problems with him I denied him of his mother language I obstructed him in his development (CO3)*

In sum we found that the "good parent" and "good citizen" argument led to a dichotomous moral landscape, which translated decisions into choices of adherence. Parents who considered mainstreaming or improving oral-aural skills were depicted as "dissidents" while those that adhered to DC-ID demands were praised.

Discouraging involvement & the dismantlement of parenthood

The previous section revealed that the DC-ID argument evolved into a moral imperative prescribed by deaf ecology. As such parents were strongly encouraged to adhere to the script outlined by deaf ecology casu quo discouraged from dissenting from it. Such a situation may be suggested to discourage parental involvement, perhaps because parental involvement is more likely to be pragmatic and child-centered.

Indeed, in particular the Signing orientated deaf schools did not appear to appreciate parental interference. Parents were hardly involved in the education of their child:

> *M: They demand too little from us as parent I feel that, at normal schools a much larger contribution is expected from parents, as remedial teacher or something else. [...] They just do not ask you [to contribute]. (C11)*

Some parents even spoke about active methods to discourage involvement.

> *M: If we want to organize a parent meeting at the institute, we now suddenly have to pay for it. We are forced to use the gym We are not allowed to deliberate in advance. They are scared to death that parents will join forces against the institute (CO3)*

The lack of parental involvement went hand-in-hand with a high sense of self-assigned authority.

> *M They are extremely paternalistic: "we know what is good for your little child mam." (CO1)*

When parents considered mainstreaming and failed to inform deaf school about this the result was:

> *F: I failed to call in deaf school It was not my task as parent It was their task, they had people for that and they decided if a child would be mainstreamed or not. I was wrong to arrange it. They would decide. (C7a)*

The attitude at institutes towards parents was generally reported as being negative. Many parents experienced serious contempt for their position. Parents sensed that deaf school personnel minimized their pedagogical and emotional value to their child. Clearly deaf schools and some deaf adults were experienced as challenging parent's capacity to judge

what is best (Darling 1983). Parents were rendered "incompetent" to make decisions for their children.

> *F: I feel that they want to see us as lay people. I feel that they want to be the ones who call the shots. If we as parents say that we want to do things differently, I feel that they do not fancy that. (C14b)*

> *F. You are the ignorant parent. They studied for it. Social workers and "integration-experts". They all work conforming to theory, pure theory. (C7a)*

This latter attitude was also identified in a wider circle of individuals in deaf ecology. Particularly some Deaf adults were experienced as hostile indeed, though one parent expressed the belief that the deaf people who visited meetings represent a minority of the deaf population (C13). Incompetence was rather inexorable in the view of Deaf adults since it was ultimately suspended from parents' hearing status.

> *F: Deaf adults were arguing: "we speak sign, the mother language of your child and therefore we know better what is best for your child than you know as parent." (C13)*

> *M: Yes, you had all those grim meetings by those, the core group [of Deaf adults - ccw]. They had an enormously oppressive impact...(CO1)*

Particularly parents in the northern and western regions appeared to be confronted with the silent notion that their incompetence was unbridgeable indeed, however hard they tried.

> *M: It is scary you know, like 'we Deaf all together' and the hearing parent and, they are very much against hearing parents, because we do everything wrong with our deaf child. (CO5b)*

The most powerful examples that parents provided were chronicles from a cochlear implant conference at which several deaf people attended:

> *M: When she [Deaf spokes person-ccw] said: "I speak the mother language of your child, so nobody will ever be able to understand your child better than us, the deaf. You will never understand them like us, because you do not speak that language". That was a stab to our soul. (C13)*

The fact that deaf ecology stresses the socio-emotional well-being of deaf children so strongly and argues that enrolment in a deaf school is mandatory to achieve this, was interpreted by some parents as evidence that they themselves were assumed un-able to care of this most fundamental aspect of their young child's life. Attacking parents' capacity to provide in this vital aspect reveals an assault on the legitimacy of the parental position.

It thus appears that the expertise claimed by deaf schools has been inflated, has infiltrated the most intimate parent-child relationship. This penetration reduces parental significance to a bear minimum and appears to be well beyond the expertise that can reasonably be expected from deaf schools Thus, deaf school expertise is not restricted to education matters in a narrow sense, but has been expanded to involve and dictate a great many aspects of life, thereby virtually establishing a sort of surrogate parenthood This gave rise to a battle over tutorship.

> *M If you are not careful your parental task will be taken from you My attitude was "all right, you may know a lot by experience, but it is my child and I decide' [ ] The core message was "you are rudimentary to the further life of your child just leave the child for us to take care of" (CO7)*

> *F Yes, you feel powerless as parent You cannot communicate with your child, at least that is what you think, and they [the deaf-ccw] can*
> *M At least, that is what they say*
> *F It is like your child is being taken away from you a little, like "Give up, she belong to us She is not your child anymore" I state it a little blown-up but still, that message is there a little [ ] We are suspended somewhere in the back*
> *I Is that how it feels?*
> *F Yes, that is how it feels (C13)*

> *M They [Deaf adults-ccw] say that it is their world He [deaf child] belongs with them That is what they say But it is our child and nót theirs (C14b)*

In sum we found that deaf ecology discouraged parental involvement in rather broad terms Deaf ecology portrayed parents as insuperably incompetent to decide for their deaf youngsters and assigned themselves the role of uncontestable experts Parents who challenged this role were met with disregard and sometimes even unconcealed hostility. Deaf ecology authority transgressed educational issues as deaf schools positioned themselves as the ideal ecology for deaf children. Parents experienced this as an assault on the legitimacy of their position.

The threat of expulsion

In the previous sections we found that deaf ecology upheld DC-ID and its preference for a socio-emotionally orientated and secluded world and did so through a variety of ways Parents were told that any other route would result in emotional injury and it was suggested that they would risk being condemned by their child. Furthermore, parents were "stimulated" to question their moral status as parent if they considered alternatives and were condemned of being a "dissident" when they actually effectuated alternatives. Finally parents were actively held-off with disregard. Yet we found an additional "method of enforcement" so to say: the threat of expulsion

When parents considered alternatives, conflict arose with school staff. Yet parents are dependent on the services provided by deaf schools, much more so than they are from regular schools. As a consequence, conflict was experienced as a threat.

> *F: Well, we had some discussions with the teaching staff Fierce discussions even. And they just made you feel like: "you better keep quiet since there is no other school around". You really taste that.*
> *M. Yes*
> *F: At a certain moment I decided not to debate anymore, since it could harm my daughter. (C7a)*

> *M: Well at first they were very angry. Because we visited IvD just to inquire about things when he had just become deaf. And they were angry that we did. We thought. "wow, we have to be careful now". (C12ab)*

This attitude was particularly threatening since parents realized the "experimental" nature of issues, such as mainstreaming or transfers to oral schools for the deaf, very well. Parents hence recognized the possibility of failure, which would imply a return to the original deaf school. As a result parents were hesitant to sacrifice their relationship with deaf school.

> *F: The school [signing deaf-ccw] did not exhibit any interest in what we were doing [mainstreaming the child-ccw] and we also did not have the impression that they would welcome us back like: "can we do anything for you?" We left and to them it was like: "you made a choice, we respect that but you are on your own now" (C9a)*

> *M: We were known [at deaf school-ccw] as parents who traveled all over to get information.*
> *I: Did they ever respond negatively?*
> *M: No, but we always aimed to keep things a little friendly, because we thought: "that door must remain open" (C10ab)*

Interesting in this context is that two parents explicitly asked us how the interview material was going to be processed before providing their personal and critical view on the state of deaf schools (CO1, CO7).

> *M: What are we going to do now? Are we going to open that cesspool? (CO1)*

> *M: I do not know what you are planning to do with these tapes but...*
> *I: They will be transcribed I will paraphrase, but anonymously [...]*
> *M: On the other hand, it does not worry me that much. It is good for them to know. It is something over which I have had many arguments. (CO7)*

In sum we found that the dependency that parents experience in terms of the services provided by deaf schools sometimes led to compliance. Parents feared that an active

exploration of alternatives would compromise their relationship with deaf school, which in turn could injure their child

Specific issues, cases and controls

Indeed it appears that our suggestion of a regional factor has some validity Regarding the persistence of DC-ID and adherence to a secluded socio-emotionally orientated world for the deaf, *all* utterances were by parents residing in the northern or western regions of the Netherlands Regarding the appeal to the Good parent argument a similar trend was found The statements by parents residing in the southeastern provinces did not refer to deaf school personnel but to statements made by Deaf adults instead Regarding the issue of adherence two utterances were by parents residing in the southeastern provinces Yet one of these parents had resided in the western region of the Netherlands during her child's early years (CO3) while the second had a child that attended a Sign language orientated school for the hard of hearing (CO5b) Regarding the issue of the discouragement of parental participation we found utterances by the same two parents mentioned above Finally, all statements in the paragraph on expulsion were by parents residing in the western and northern provinces No specifics are reported in terms of case-control status of the child's age

Conclusions

In this section we found that deaf ecology upheld DC-ID and its preference for a socio-emotionally-orientated secluded world, regardless of maturity or context In general we encountered a persisting low-challenging philosophy and a lack of guardian values In an analysis of the utterances in this section we found a predominance of parents residing in the western and northern regions of the Netherlands This outcome is congruous our findings in chapter four, where we described that DC-ID utterances were expressed by these parents mostly This finding supports the thesis hinted at in the introduction of this chapter the two schools for the deaf in these regions are rather strong advocates of an encompassing DC-ID discourse

DC-ID discourse was supported by several arguments and strategies Firstly, parents were told that alternatives would result in emotional injury It was also suggested that if parents explored alternatives they would risk being condemned by their child Yet deaf ecology proceeds well beyond these issues Parents were "stimulated" to question their status as good parent or good citizens if they considered alternatives and they were condemned of being a "dissident" when they actually effectuated alternatives Furthermore parents were actively held-off with disregard Finally compliance was achieved through a threat of expulsion

The principal element of deaf ecology discourse pertained to the concept of "acceptance" Parents were prompted strongly to "accept" their child, of course this is meant as accepting the child as being a deaf child Yet this summation does not tell us very much since it can be interpreted in many ways Psychologists for example may be concerned over the parental coping process when alluding to acceptance Others may be more concerned with the moral aspects of the issue, which seems very much at the core of popular child rearing ideology parents are expected to "naturally" experience unconditional love for their offspring, whatever his or her "being" is (i e "to me this is the most wonderful child in the universe") In the case of a deaf child, this "being" is deaf and parents ought to love and cherish their child in spite of it In this sense the issue of acceptance is of great interest since it is linked to some generic defining state, a state that is considered "intrinsic" to deafness – an issue on which we will elaborate in chapter seven As we have shown in the previous chapter however, most parents say that they do indeed experience authentic love and affection towards their child in spite of the fact that he or she does not hear In this respect one could argue that they fulfill the moral requirement posted to them In spite of this, many parents did continue to dislike the limitations that deafness raises for their children, which may be depicted as a proof of conditionality and as such may be a source of confusion

However, if every feature of a child is essentialized or perceived as an identity trait, the demand of unconditional love likely results in a form of "parental paralysis" since it grants a child unlimited autonomy Isarin argues that this state represents a radical uplifting of the "who" of the child that needs to remain "untouched" and "uncontaminated" (Isarin 2002) She further argues that this in fact re-essentializes the disability and as such is much like the essentializing that we discussed previously in the context of equating the "who" of the child to the "what" as defined by our social prejudice on disability *Both* are in fact encompassing narratives

> Park and other mothers of autistic children are immediately placed in a dilemma that most other mothers never have to face She can either struggle to normalize her child, to bring her into the "human condition", as she says, and attempt to make her into a socially acceptable adult But if she does that too insistently or too strictly, the child quickly gets the message that she or he isn't all right ( ) On the other hand, such a mother can appreciate her child's difference, value it as an acceptable difference, in which case the dangers are just as great Here she may run the risk of romanticizing her child's abnormality, even "giving up" on her child (Isarin 2002 - translation ccw)

Indeed this section showed that deaf ecology is inclined to "essentialize" deafness DC-ID's extended pragmatic claim on vulnerability becomes solidified and as such essentializes deafness Deaf children were depicted as special casu quo "vulnerable" children to whom different standards apply and who demand a protective environment since, as one parents paraphrased a deaf counselor, "they have such a tough day as it is" This is to say that a deaf individual is a priori considered vulnerable, which in turn calls for extraordinary precautions These extraordinary precautions in turn will steer the

future of deaf individuals in a very distinctive direction: it thus more or less presets expectations, it predetermines "who" a child can become. Moreover, the "who" that the child is predestined to become is out of the ordinary and is at odds with some of the values held highly in society, such as independence and self-reliance. Yet the essentializing tendency was most obvious through the identity and cultural arguments of DC-ID. Deafness was depicted as an existential trait, which yields the moral ("good parent") and moral-political ("good citizen") duty to safeguard it. The result of this process of essentializing is that the state of deaf children is cast in a dualist scheme that focuses on parents' "attitude" or "moral character" rather than the well-being of deaf children per se. Parents have to choose: choose to be an "unconditional loving" parent or not, choose to be a "tolerant" parent or not, choose to be a "caring" and "child-centered" parent who primarily aims to optimize their child's emotional well-being or not.

Though the *intensity* of the DC-ID discourse is unlikely to be experienced by parents of normal children, the general values depicted here are not restricted to disability (Eyer 1996). Yet they do seem rather abstract or symbolic in nature, perhaps - as we mentioned in the introduction of this chapter - more fit for parents of young children who lack a "concrete child" and as such may be keener on symbolic expressions of their parental qualities. Furthermore we argued that parents of older children are likely to include guardian values in their general parenting attitude. This suggests that parents may not share the views expressed by deaf ecology when they become more experienced and their child matures. On the other hand, the DC-ID discourse impressed us as muscular and influential, something parents residing in northern and western regions cannot simply disregard. In the next section we will analyze the utterances of more experienced parents to shred light on this issue.

THE CHANGING PARENTAL PERSPECTIVE

Introduction

In the previous section we concluded that a strong DC-ID discourse dominated at deaf schools in western and northern regions of the Netherlands. Though we suggested in the introduction of this chapter that parents are likely to change their child-rearing perspective as a child matures, parents residing in these regions will have to deal with DC-ID as well. In this section we will analyze how parents viewed their deaf child as he or she matured. Did parents' view indeed change as their child matured and was region casu quo the intensity of DC-ID of influence on their view? The first question implies that we are interested in parents of older children primarily, which we defined as children 8 years and up. The next cases and controls fit this description.

Cases ≥ 8 years of age (at interview)
- C1a, C3b, C4ab, C5a, C6, C7a, C9a, C10ab, C11, C12ab, C15, C16b (n = 12)

Controls ≥ 8 years of age (at interview)
- CO1, CO2, CO3, CO5b, CO7 (n = 5)

Excerpts by cases and controls that don't meet these criteria will be printed in bold.

In the previous section we depicted three central essentializing arguments in deaf ecology discourse, arguments that clustered around the issue of "acceptance". Added to these arguments we have shown that deaf schools sometimes minimized the role of parents in the upbringing of their children and implicitly "misused" their monopoly position to restrain parents. In chapter four we argued that the bilingual thesis played a strategic role as well. As such the next elements can be identified as parts of a more complete description of DC-ID:

DC-ID arguments
- Essentializing vulnerability: care or child-centered attitude
- Essentializing deafness as an identity-trait: unconditional loving attitude
- Essentializing deafness as an ethnic of cultural trait: tolerant attitude
- The promise of Bilingualism
- Deconstructing parenthood
- The threat of expulsion

If parents' perspectives are to change, they must deal with the demands posted by the DC-ID argument first. It seems unlikely that parents will move beyond the prescriptions of their deaf ecology unless they formulate an adequate answer to these demands. In this section we will analyze how parents viewed their child's vulnerability, how they perceived the relation between deafness and acceptance and how they dealt with the

projection of deafness as an ethnic relevant trait We will also scrutinize if the promises of bilingualism were upheld and how parents responded to the minimal role granted to them. Finally we will discuss the values that parents propagated when their child matured· did parents persist to centralize care values such as emotional well-being or did guardian values such as independence, autonomy and achievement gain influence?

Deafness and vulnerability

When asked how parents perceived of their deaf child at present time as compared to possible other hearing siblings, most confessed that while their deaf child at times did receive preferential treatment, this was mostly pragmatic rather than generic or attitudinal (Rorty 1990; Philp 1982) Many parents expressed the opposite· they expressed an almost principal preference for a "normal" attitude their "tonic" attitude so to say was one of normalcy (Bell 1977; Paul 1993) Parents did not a priori assume that their child was more vulnerable or in need of an exceptional protective attitude. Hence no different measure stick or standard was employed to establish the difference between "demanding" and "overly demanding" Parents were motivated by several factors to assume this attitude Firstly, parents seemed to despise a protective attitude in itself and felt that it was stigmatizing and counterproductive Secondly and more pragmatically, parents sensed that a protective attitude was not appropriate in the context of their individual child.

Vulnerability as stigmatization

Parents did not fancy the encompassing protective attitude that they encountered in deaf ecology One of the chief explanations was rather similar to what we discussed in chapter four vis-à-vis the pitiable stereotype of deafness The pitiable stereotype of deafness claims the "who" of the child, reduces his or her existential space and suffocates individuality Likewise, the maxim of vulnerability of DC-ID invades the "who" of the child, something that parents resented

> *F They should not be branded a priori [ ] (C15)*

> *M They are placed on a small pedestal at [Sign oriented] deaf school [ ] A small pedestal with a sign like "I am deaf" Well, I did not want that (C7a)*

The encompassing DC-ID argument thus limits a deaf individual's opportunities and existential space to the omnipresence of the assumed vulnerability

> *M We just provide him the opportunities and do not push him into one direction a priori Like "OK, you are deaf and now we are going to patronize you and protect you and make sure that you will never meet the great bad world So just go on and live in the Deaf world" [ ] I think it is a denial of your child a denial that he is your child first and deaf only second (CO5b)*

In this respect the pitiable prejudice and the vulnerability axiom appear to be two versions of the same story really Parents thus sensed that to adhere to the maxim of vulnerability would result in an endorsement of stigma really As such they tried hard to avoid it

This was true for typically demanding situations as well Social interaction with hearing peers for example, is likely rather demanding for a deaf child and as such may trigger parents to encourage a more "forgiving" attitude from those engaged with their child Yet even in such circumstances parents avoided doing so

> *M No, not at all [special position in neighborhood - ccw] Not at the clubs he attends either We had long discussions there [at hearing sport club-ccw] about this very issue, making clear that we absolutely did not want that, that they placed him in a special position (C3b)*

Rather parents preferred the path of providing information about the limitations raised by the "what" of deafness so to say This was illustrated by parents' response to incidental social miscommunication in the neighborhood parents avoided a response appealing to generic vulnerability (i e "you should not bully him because he's deaf"), but rather chose to explain to those involved *why* miscommunication occurred and how it could be prevented

> *M There's a lot of talking when conflicts arise [in school - ccw] when children do not understand him if he gets into a fight, they just talk about it But, well, sometimes it is just his fault You have to help him understand I mean if someone tells him ten times to walk on and he does not, the eleventh time they will push him I know he will not understand that and may want to push back Instant conflict! So I talk with the teacher about that, because I do not feel that parents should get involved as well*
> *I Why not?*
> *M Well because eh, I just do not fancy overly concerned parents I do not like parents who walk behind their child all the time like ' this is my kid and make sure you handle him in this or that way" [ ] We had situations like that in our neighborhood as well When a friend would stay over at one of the neighbors The child does not know the game and the rules of course This often leads to problems We just sat at the table with the children then and talked about it we said without using his deafness as an excuse that this situation is special he just does not always catch everything the first time around (CO5b)*

> *F One family in the neighborhood did not like to be disturbed when eating dinner, they would not answer the doorbell If our son would want to play and rang the bell they would just leave him there sitting and waiting for 10 minutes*
> *M In front of the door*
> *F He would think the bell did not work and sat down until someone came out I find that annoying and pitiable You disregard it for some time but at one point we approached them like, "even if he is deaf you can surely treat him normally can you' You would have*

done the same if it happened to a hearing child That kind of situation, yes I did something about that (CO5b)

Parents feared that a protective attitude could become pervasive. If a young deaf child is raised in an environment that endlessly approaches him or her as potentially vulnerable, this is likely to become internalized

I What is your policy with your children? What one is allowed the other is too? Or do you feel that because she is deaf she is a different child?
M oh, absolutely not!
F No no
M Absolutely not, no The same way as when I would have had two normal children The older one goes to bed later than the youngest for the rest we have the same rules
F No, no preferential treatment Even though she is deaf No, because that is destined to run out of control (CO5b)

M Some time ago the results from a study were published it was an eye opener It was shown that if one demands so little from deaf children they will conform It is not that one demands less because deaf children are less capable No, deaf children sense that little is expected from them, so they achieve less That is turning things upside down (CO7)

Some parents indeed disclosed that their deaf child at times did appeal to "special rules" to exempt them from everyday demands or obligations Parent did not fancy this and did not honor such appeals

I: Does she ever use her deafness?
M: Mis-use you mean?
I: Yes
M: Of course. But I do not think that is exclusive to deaf children.
I: No. How do you respond to such situations?
M: Like we would in the case of a hearing child, I mean we discourage it. You do not accept it. (CO6b, 7 years)

M When he was 11 years old he would sometimes make use of it, like, eh Yes but I cannot do that, because I am deaf" I would say 'that has nothing to do with your deafness you just do not feel like it" (C3b)

Parents also appeared to reason that a deaf child benefits from a self-image that is "realistic" rather than engulfed by protection

I You wanted them to
M Yes Just normal He is deaf but that is it He does not need extra privileges, cause that will not make things easier as a grown up (C3b)

Hence parents reasoned that a deaf child that internalizes the low-challenging axiom will not only metaphorically but also physically be sidetracked at an adult age, again emphasizing stigma. The lack of educational challenge, typical of some deaf schools, *must* coincide with the acceptance of low educational output and ultimately a poor societal outlook. Indeed, some parents felt that deaf schools accepted this social outcome of their protective truism.

> *M: They assume that...*
> *F: They will work in the shoe industry.*
> *M: It is a deaf child, so there is little [to expect]. That [idea] is really strong there [deaf school-ccw]. [...] Last week I heard about a parent whose child attends school in Groningen, he is 14 now. They [school-ccw] feel he is a child for the social work place so they just let him stroll through the last years [of school]. That makes me think. you can't do that as a school It is a scandal that they feel that way! [...] When you hear that 93% of the [deaf] children between 13 and 17 attend special education and only 7% higher, that is to cry! (C15)*

> *F. We accused the school staff of departing too much from the premise that deaf children lack capacity rather than the idea that they can do a lot but are limited in some areas. The world upside down. They are deaf so they cannot. Nonsense. (C5a)*

> *F. Well, I think they hold rather low expectations. If a deaf student graduates from a hearing high school the flag is raised which makes me think. why would a deaf child nót be able to graduate from high school? (C6)*

> *F: They stimulate that at deaf school [becoming a baker].*
> *I: How is that?*
> *F. They have the largest hosti bakery in Europe, they have a bakery which serves the whole world you know. (C3b)*

> *F: At deaf institutes they assume that we should be glad if he goes to high school, they hold the yardstick rather low for understandable reasons. (C11)*

As such the low-challenging philosophy is clearly not restricted to childhood but invades deeply into adolescence and adulthood. If the maxim of vulnerability is carried through, the consequences are significant and rather permanent.

The inappropriateness of a protective attitude

Even though parents may feel that the protective maxim of DC-ID is stigmatizing or unwanted from a general perspective, this in itself is unlikely to be convincing enough. After all, one of the main arguments of this element of DC-ID is the assumed vulnerability of deaf children. As we showed in the previous section, at least during early childhood the arguments in support for this state of vulnerability were rather convincing to parents. However much one may despise the stigmatizing results of DC-ID, if vulnerability proofs to be an empirical *fact* one cannot simply discard it. This implies that

parents must also formulate an opinion in the domain of their child's realistic vulnerability. While parents of young children must rely on theoretical or intuitive knowledge, parents of older children can actually measure the appropriateness of the low-challenging adage: parents of older children can gauge the impact of specific challenges hands-on.

Indeed parents developed a sense of what their child was capable of as well as a notion of what he or she could handle from an emotional point of view. As such parents steered away from the implicit DC-ID premise that any challenge imposed by deafness constitutes an "excessive" challenge. Rather parents viewed challenge much more generic, in much the same way as one would expect in the case of a non-disabled child. The merits and liabilities of a *specific* challenge were determined on a case-to-case basis that was rather insensitive to the *origin* of the challenge (i.e. deafness). Thus, parents did not view a challenge instated by deafness categorically different than a challenge instated by, let's say, a child's lack of athletic capacities: both were perceived as challenges with a specific caliber that needed to be met by an individual child with a specific range of potential and resilience. Parents thus appeared to evaluate the weight or impact of a particular demand based on its specific characteristics rather than a priori assuming that any demand instated by deafness would transgress their child's resilience. Thus, determinants of this appraisal were the assumed capacity of a child to deal with challenge cognitively as well as emotionally.

In terms of cognition, parents learned that individual variability is considerable amongst deaf school pupils and that these differences matter in terms of what one can demand from an individual child. One of the main conclusions many parents draw is that the developmental scope of deaf children is not as monolithic as suggested by deaf ecology but broad and highly individualistic indeed (CO1).

> ***M: There are a lot of differences. The individual person is an important factor. One person may learn very easily while it takes the other considerably longer before they speak a single word.***
> ***F: They are not all the same.***
> ***M: You find that and you learn a lot from it. (C2b, 5 years)***

> *M: Those children are all so different in terms of capacity, you just have to handle things on an individual basis really if you want it to be good (C10ab)*

> *F: We are still thinking too much in terms of compartments. Deaf is deaf, so they should go to school in Amsterdam. Or you place them in boarding school in Groningen, at the institute [...] It is very dependent on the individual child and on the specific situation*
> *M: And the home situation.*
> *F: It is very dependent on the characteristics of your child. They are not all the same (C5a)*

Regarding spoken language potential for example, parents discovered patterns in the sample of deaf children available to them. In particular parents of children attending a school for the hard of hearing soon learned that the degree of hearing loss is an important confounder of spoken language potential.

> ***M: Many of his classmates are hard of hearing.***
> ***F: You notice that they are faster, are more advanced. There are kids of whom you would not think that they have a hearing disability...***
> ***M: Yes, they speak real well. You see them entering school and one goes in one direction and the other a different direction. Some just proceed much faster even though they were enrolled simultaneously.***
> ***F: It depends on hearing remains and our son has non. (C8b, 5 years)***

> *F: One thing was clear from the start...every time we entered a classroom situation and observed how well the children spoke we were told that these were children with hearing-remains. That distinction became increasingly clear to us. (C9a)*

In general terms of "challenge" (hence not spoken language potential), many parents felt that their child was able to handle much more than offered by the deaf school curriculum. This implies that parents did not reject the low-challenging atmosphere per se, but rather felt that it was unfit for their individual child.

> ***F: Well...I have great confidence in her capacity. In the sense that I think she is very musical, strange enough. I have that feeling and I also think that she is extremely smart and has an enormously strong mind. (C13, 4 years)***

> *M: She does not fit there [signing deaf school-ccw] in terms of her abilities. (C10ab)*

> *F: We feel that he is a smart little guy, I think he even excels in some areas. I think his educational opportunities would be similar to his sister if he could hear. That means he would attend college-preparatory training.[...] But that is not how he is addressed at school. (C11)*

> *M: I was not satisfied with [Sign oriented] school. I was content with how sweet they were with the children, which gave me the feeling that he was in good hands, but they were not challenging him at his level. (C12ab)*

> *M: My child was able to draw. At the school she was given a small notebook that said, "Today we worked with blue and yellow". A week later the same thing. We felt like. come on guys do something. Work at her language, don't work with her at that level, which she has surpassed long ago...We addressed this with the teacher. She did not see the problem. She felt that the children just had to play, just had to engage in fun activities. But she can do that at home as well, she can play with children in the neighborhood, I can take her places. So we did not see the point of that school (C10ab)*

One of the explanations was that deaf classes often cluster a broad range of children in terms of capacity and that the level of challenge offered is determined by the median

> *M It is real hard if your child is grouped with congenitally deaf children and children who have additional handicaps*
> *I They all attend the same class, also children with additional problems?*
> *M Children with behavioral problems*
> *I In one class?*
> *M Yes, they are grouped based on age alone, they did not have the capacity to do something else (C10ab)*

> *M You can taste that at school I think there are a lot of children there who are much worse off than he [deaf son] is which legitimizes all that attention And that is very hard because we feel that our child is harmed because of that we feel that all has to be done to get him to the level where he would be at if he did not have that handicap But the percentage of multi-handicapped children is large, which draws the level downward (C11)*

Deaf schools on the other hand sometimes seemed to refute the significance of individual variability, contested the view that some pupils are capable of more than the level offered by the school curriculum

> *M I recall that I met this woman who worked with gifted children and asked if she was interested in deafness She asked me some questions and told me that she would visit the [Sign oriented] deaf school to ask if she could contribute because she worked with gifted children Their response was ' We do not have those here ' (C11)*

In terms of emotional resilience, parents seemed to believe that the challenge posted by more demanding experiences than the deaf curriculum allowed did *not* a priori meet the requirement of "overly demanding" Rather parents seemed to assume that such demands fell within their child's scope of resilience Parents did not discard emotional concern all together, yet they gauged it on an individual and case-by-case basis Emotional well-being remained the perimeter of what parents planned, yet parents' view on this perimeter differed from what deaf schools apparently assumed

> *F We are convinced that, if we look back at the past 6 years of mainstreaming that she has been very happy and that is what counts That she is happy, enjoys going to school, feels comfortable about herself While still having a positive outlook on the future [ ] She is mainstreamed for 6 years now and has never said that she did not want to go to school She always enjoys going, takes part in all the activities though she is very much aware of her special position The other way around I think she is well accepted by her peers We never noticed bullying or anything like it If I watch TV programs about non-handicapped children recounting their grade-school frustration I feel like well she [deaf daughter] does not make the impression of a frustrated child (C9a)*

M Of course, the main concern to us was that she is happy, but we felt like she could be challenged much more (C10ab)

M Sure, I make sure he gets his freedom [to play-ccw] but it is all about the harmony in which things are cast (CO1)

While parents of younger children seemed more sensitive to authoritarian views on their child's assumed resilience, in time parents increasingly trusted their own observations and instincts.

M As parent you know what is best, what your child can and cannot handle I think we can evaluate that very well You just notice from their behavior if something is wrong So we had frequent contact with the school, asking how things were going If things were not well, we would be the last to force her to stay in this class, we'll just take a lower level with her (C15)

M I think that as parent you are the best judge You have an instinct for that I think that they should listen to parents much more Everything that we suggested and which was fought off [by the school-ccw], which they did not want to see, proved correct in the end (C10ab)

F Throughout the experience we took decisions based on intuition and reason several times We resisted the claim of experts that things ought to be this way or another [ ] If we had the intuition that it was sensible to do certain things, we did (C5a)

As a result, the idea that deaf children ought not to be challenged was released more and more. The threshold for "reasonable" challenge increased as parents actually witnessed that their child was doing well with the challenges offered. The notion that a challenge imposed by deafness is categorically different from challenges in other domains was released

M If you notice that something is easy for your child, you try to expand the limits, offering more If she would at a certain moment attend mainstream school and would come home one day to say "I do not want to go there any more because I have to work too hard" I would think "Come on now, hard work? We áll have to work hard" [ ] Look, my children do not have to come home from school all worn-out But I have never seen them coming home tired So one day you'll think "wow, I worked hard today', but that is OK We all have days like that (C15)

F You must demand things from them sometimes Like you demand that your children wash their hands after visiting the restroom They will not do that spontaneous, may not even like it But if you do not [demand], if as parents you feel that you ought not, I think you will have a hard time I think that is crucial (C5a)

Parents thus came to see the challenges imposed by deafness as "general challenges", much like one would do in the case of non-disabled children and recognized the threat of

"parental paralysis" if the "who" of the child is considered sacred (Isarin 2002). Like in the case of non-disabled children, "challenging" was perceived as perhaps not the "natural" inclination of deaf children but something that *can* be and needed to be done nonetheless.

> *M: When I was young I had to do homework every day. There is nothing wrong with that. You just should not make a coercion of it. Surely one can make a deal with one's child Like: "you just have to work much harder at it". My child understands that very well. He understands that he will have to work hard if he wants to learn to read. But I always stimulate him. I take him to the bookcase and say: "you will be able to read all that!" (CO1)*

> ***F: Why spoken language? It is just necessary. We had to go to school when we were young too and we did not like it either. (C2b, 5 years)***

> *M: I try to push her as much as possible, like "you have got to fight for it, you will have to work for it " (C15)*

Most parents sought a balance between the "genuine" vulnerability of their child and excessive "generic" protection. Yet this is not an easy distinction to make in this context. On one extreme it could imply a rather encompassing script in which the child is structurally reduced to a "special" and "vulnerable" child, which parents associated negatively with an "over-protective" attitude.

> *M. They [some deaf children] are not allowed to go to town by bike. They are not even allowed to learn to ride a bike because parents find it to dangerous, because "you are deaf, you cannot do that". (CO5b)*

> *M. I think protective parenting is on the rise amongst young parents. I do not agree with this. I really feel that children can handle more, that you can demand things from them. (CO3)*

> *M: Look, you have resilient people and less resilient people everywhere...You should be careful not to blame everything on deafness. That is unreasonable (C6)*

One parent spoke of "neglecting the handicap positively" (C5a). With this utterance this parent seemed to allude to neglecting the dominant and generic assumption that deaf children "cannot do".

On the other extreme it could imply ignoring the *real* limitations that deafness provokes in an individual child. Parents did not ignore these limitations, yet tried to tackle them individually and on a case-to-case basis. In general parents thus felt that it was difficult to *pre-dict* if special measures were called for. Parents did not a priori determine if a specific situation was too challenging for their deaf infant but took a more pragmatic

stance of trial-and-error. This implies that the child was in principle encouraged to engage in potentially stressful events.

> *M: If you [a priori] say, "you cannot do this because you are deaf", well I mean just try it first. Maybe he cannot do it but maybe he can very well. And...you only know if you try. (CO5b)*

Deciding on which challenges to offer and sustain was therefore a highly individual and contextual undertaking.

> *M: You have to plan things individually I think. You are dealing with a unique child, try to do something with him or her. (C4ab)*

> *F: It is impossible to lay it out in a flowchart, there just are so many factors to consider. But we always wanted the best for her and we always looked at things that way. (C9a)*

This implied that parents were constantly "on the move" so to say, re-evaluating the situation relentlessly.

> *M: I still keep comparing, researching. I am always curious and want to know about "the other story". Why other people make a choice for the oral method just as consciously as we did [for Sign language]. I am always curious and keep balancing things I am convinced about my decision, but it is just in my nature to keep looking you know? (C11)*

Parents suggested that the trial-and-error experience had revealed that much more was possible than they had anticipated. Even "tasks" that seem rather incompatible with deafness, such as enjoying music, were sometimes included in this aim (CO3).

> *F: If you succeed to neglect the handicap positively like: he is deaf but that does not mean that we should not offer him music. It should not mean that we refrain from stimulating him to feel the vibrations of the speakers, feel the rhythm. If you just keep trying to do what you would have normally done and invest that extra energy - because it goes slower of course - you'll find that much more is possible that you thought. (C5a)*

> *F: His brother was playing the flute and he wanted that too We did not feel it was necessary to tell him that he could not, because he is deaf. So we inquired with friends at the music school if they thought it was possible. They thought it was. [...] He attends the music school now He takes keyboard classes. We know he will never be a concert pianist but it is just like, eh, evident impediments for those children. Like you don't do that with a deaf kid. We want to show that you may be deaf but that does not stop you to learn notes now is it.*
> *M: Yes because we never felt that way. We never felt like "you cannot do that because you are deaf." (CO5b)*

Parents sometimes experienced first hand how their individual child actually enjoyed a challenging environment, thereby relativizing the need for avoidance of challenge that we depicted in the context of the deaf school environment.

> *M We experienced that [ ] Attending the training sessions at IvD we could see time after time that he was very much not tired at all And activated, he enjoyed it a great deal*
> *F Working hard all day, tests, experiments and doing a lot of things*
> *M He enjoyed that [ ]*
> *F He had to perform at the top of his abilities His limits were being explored all the time He would be inspired after such a day! (C11)*

Some older children actually expressed dislike over the lack of challenge at deaf school themselves, casu quo expressed the desire to attend mainstream education

> *F He indicated it clearly, like 'what am I doing there, I do not like it' It was boring him, too easy (C5a)*

> *M He was 9 or 10 when he noticed he was different [having an above average learning potential-ccw] And he wanted out of the jail of deaf school, he thought the children there behaved rather strange (CO3)*

> *F She wants to attend regular school She is pressuring us more and more (C7a)*

> *M At a certain moment she said 'I don't like it there anymore" She did not want to miss out on activities here [hearing school-ccw] [ ] She indicated it constantly, that she did not feel comfortable there anymore, did not feel in place there (C10ab)*

While parents initially did not consent as they worried over the challenge mainstreaming would pose and questioned the motives of their child (CO7), most eventually agreed

> *M We let things [the way they were] for some time but eventually withdrew her [from deaf school-ccw] We talked about it at both schools and, well if she does not want it if she enjoys it [hearing school-ccw] more [ ] I said to her ' but you will not see your deaf friends anymore" She responded saying "So what? I have my friends here and they [deaf friends-ccw] live so far away, what good is that?" (C10ab)*

Yet this individual and contextual evaluation of the challenges faced by a deaf child can, by definition, not a priori lead to increased demands Indeed we found this to be the case For some children the demands posted by engaging in social interaction with hearing peers or attending mainstream education were simply judged to be excessive

> *I How are things socially, with his peers in the neighborhood?*
> *M A lot of fighting It does not work well He has two friends now with whom things go well But they sit behind the computer mostly and that does not require much communication (C12ab)*

M The older they get, the more they will need their communication He has no trouble with adults, but with peers he has to deal with macho behavior and that does not work out well at least not in the large class he was in (C12ab)

F Well, he jokes around, plays games [at hearing school-ccw] That is too bad It makes his handicap so visible Because he is not able to do anything else but that Because he can speak a little but he feels shy about that And the question is if the other [hearing-ccw] boys would understand him (C11)

One parent mentioned social isolation at a school for the hard of hearing as well

M Children talk a lot and she could do little with words and would end up in isolation
F [at the school for the HoH - ccw] they taught her things and she did fine But when they had to choose groups, they [fellow students - ccw] would ignore her And at the play yard she was a loner These observations made us question if she was at the right place (C15)

This experience eventually resulted in a transfer to a signing school for the deaf

I What was the reason for the transfer from the school for the Hard of Hearing?
M Well, her social-emotional side right
F The social aspect (C15)

Another parents withdrew her child from the social-integration program for similar reasons

M The older he got, the less he liked it They had huge classes with almost 40 students, so it was impossible for the teachers to give him the attention he needed This is not a reproach towards the teachers but it is just the way it is The teachers also had less intuition how to deal with a deaf child Had less time to explore it [ ] So we tried a Sign translator They start the day of with a circle discussion, a bible story of half an hour followed by another half hour of debate He would just not benefit from that since the kids would all talk at once So the translator came especially for the circle discussion and the bible story They would leave after an hour and things went pretty good Until suddenly we were unable to get a translator even though one was appointed to us There were none available [ ] So he sat there without a translator well that does not work So we stopped with it With a lot of pain in our heart (C12ab)

Alternatively, some parents felt that mainstream education yielded too few benefits

F Even with a translator she would still likely fail if we mainstreamed her five days per week You have to be realistic as parents
M The curriculum [is too demanding-ccw]
F She would miss too much (C7a)

Thus, attending mainstream education was *not* seen as a "goal in itself", but something that needed to yield benefits without generating excessive liabilities

M: Look, you must consider things carefully like· does it really lead to reasonable benefit? (C9a)

If the benefits were considered minimal and liabilities too great, deaf school was apparently considered the most logical option. Of course the possibility remains that these latter parents were lured by the powerful DC-ID discourse. Alternatively, different parents may operate different "thresholds" of desirable or acceptable challenge: while one parent may as a rule find it "healthy" for a child to be exposed to challenging circumstances, others may conceive of challenge more negatively. One parent for example, explained her challenging attitude in terms of her own liberal upbringing (CO3). Yet while we cannot exclude the significance of either of these factors, we have no convincing evidence to support them and thus assume that these parents reached their decisions based on a local and contextual appraisal much like other parents did.

Summarizing this section it appears that parents refute the attribution of a "special status" to their deaf child, both in terms of pity as well as in terms of an assumed and solidified vulnerability, such as described in the introduction of this section vis-à-vis DC-ID. Parents tried hard to avoid an environment in which special rules apply to deaf children as opposed to other children. At the core of this attitude lies the conviction that deaf children are in principle not much different from other children. Parents recognize deafness as a potential source of limitations and as a potential source of experiences that transgress a child's emotional resilience, but refused to reason that *all* challenging experiences raised by deafness are by definition unacceptable from an emotional perspective. For most parents socio-emotional concern seemed as a rather adequate response to the real susceptibility of deaf children to negative experiences, in part due to their stigmatized status.

Debunking Deaf ideology

In the previous section we have shown that, across the board, parents steered away from the essentializing claims of the vulnerability argument and felt that there was no need to a priori assume that deaf children are extraordinarily vulnerable, and thus no need to a priori take for granted that extraordinarily precautions are called for. This conviction refuted one of the main arguments of DC-ID and in principle paved the road for challenges beyond the recommendations of deaf ecology. Yet the DC-ID argument consists of more than an assumed vulnerability alone. As we have shown, the DC-ID argument appeals to "identity" and "cultural" arguments, which are much harder to refute based on empirics given their foundational moral makeup. Yet these "ideas" (CO7) were shown to be widely present and rather muscular, which implies that parents must deal with them somehow if they are to proceed on a nonconforming course.

A first step in this process was the identification of the "identity" and "cultural" arguments as being "ideas" with a moral structure as opposed to the "empirical" nature of the low-challenging axiom discussed above, therefore requiring a different oppositional approach. Indeed, in time, many parents identified this.

> *M If people tell me that "it should be this way" I always become suspicious. I mean, the old pillars have to be torn down and it is parents who are doing it because that is the new way isn't it. (CO1)*

> *F: It is all so dogmatic you know? You either do sign or you do this or that. But I think you have to see what is best in the specific situation at hand. (C9a)*

Parents hence grew suspicious and skeptic towards the foundational claims of deaf ecology, which paved the road for a more profound debunking of its premises. We will illustrate the details of this process both in terms of the identity and cultural argument.

Deafness and acceptance

As we argued, DC-ID linked "acceptance" of deafness to the value of "unconditional love": parents who questioned the ideal secluded world advertized by deaf ecology were negatively portrayed as parents who loved their children "conditionally". A central development that assisted parents to release themselves from the moral grip of this specific demand was discussed in chapter four: parents actually experienced an authentic loving and reciprocal relationship with their child. Parents did not feel that their love was restrained or conditional, which refuted some of the claims of the acceptance axiom.

Yet the content of the previous paragraph suggests a second development. The rhetoric of the acceptance argument lies in the fact that deaf ecology prescribes which elements exactly ought to be considered as "the reality" of a deaf child and hence which elements ought to be embraced wholeheartedly to meet the demands of unconditionality. Apparently, actually experiencing authentic love towards ones child is not good enough in terms of DC-ID.

> *F: It is really awkward that she [Deaf culture advocate-ccw] draws that distinction so rigorously: like, your child attends a deaf school, does Sign language and thát is the Deaf world. If you have deaf children that do not sign or do not attend a deaf institute, you are depicted as choosing for something else categorically. That distinction is really strong. (C9a)*

It seems that in doing so, a silent reference must be made to what is considered the "natural" state or "reality" of being deaf. Yet it seems illogical to conclude that upgrading of the socio-emotional and Deaf culture are the uncontestable hallmarks of such a state: these attributes are socio-cultural attributes by definition. This differentiates the acceptance discourse from the context of advanced cancer patients or children with

Down syndrome Advanced cancer patients for example, simply do not have the capacity to live As such it is undeniably true that for a terminal cancer patient acceptance "is not an act of resignation but an act of facing reality that allows them to respond to it" (Reinders 2000) Thus, the "natural state" of an advanced cancer patient is rather self-evident The same may be true for mental retardation It is indisputably true that there is a roof to the cognitive abilities of a child with mental retardation This reality leads to other realities, such as a decreased educational potential and, though we cross the line of social-constructiveness here, a decreased ability to engage from a societal perspective

Yet the "reality" of a deaf child is much less encompassing and coercive and as such much sooner traverses the line of social constructiveness

> *F I consider this a great privilege compared to parents of a child with a mental disability If you have a child with a mental disability it has a certain status and while the child grows older not much will change (C9a)*

Parents realized and experienced first hand that the "prescriptions" of deaf ecology are at least to some degree arbitrary and represent choices Uncompromising adherence to these prescriptions was perceived as resignation parents criticized the sense of passivity and resignation to a "care-ideology" that is blind to capacities that individual deaf children may have (Reinders 2000) Still, parents recognized that "resignation" has benefits as well

> *M We visit the parent meetings on a regular basis but I always feel a little like hey we are a little different than the others you know Because we noticed that many parents have an attitude of resignation like 'as long as they attend deaf school things will be all right [ ] Accepting yes like he is deaf and we have to lead our own lives too (C10ab)*

> *M You have to keep at it for years keep correcting offering challenges create opportunities A lot of parents start with a lot of energy doing all kinds of things But after two years they're burned up Placing their child at deaf school in a protective environment, just accepting the school program is a way out*
> *F That is understandable too (C5a)*

The prescriptions of DC-ID may however be pragmatic foremost, implying that the socio-cultural context is accepted as a given Though a lack of challenge-ability or the need for a secluded environment may not correspond to the "reality" of deaf children per se, our socio-cultural context may render them so nonetheless aiming for mainstream participation may not be "impossible" but rather "unreasonable" for deaf children Congruous with this view is the statement by deaf author Govers that "it is of the most vital importance that young deaf children are armed with self-confidence and a positive self-image" (Govers 1995) If we need to "arm" these children surely we anticipate some sort of battle, this battle we would argue represents a view of what it entails to be deaf in our society Indeed Govers believes that such a battle is inevitable confrontation with the

hearing world *will* lead to disappointment he feels. In fact this explanation overlaps with the extended pragmatic arguments that we discussed previosuly: not accepting the deaf school plan is renounced based on the psychological appraisal that such initiatives will injure a deaf child. As such the acceptance argument becomes fuzzy since it links the moral vocabulary of what is considered the "natural state" or "reality" of deaf children to the psychological discourse on emotional injury, which is much more pragmatic and empirical in nature. The next excerpt illustrates this

> *F: Well, they [Deaf culture orientated friends-ccw] have different ideas, they say "we accept deafness and aim purely at deafness, at the Deaf world, that is their world and the hearing world, well they do not fit there because they have to carry to many stones around there (C5a)*

As such the foundational acceptance argument becomes a proxy for the vulnerability axiom that we discussed above, yet in a "moral masquerade" so to say. Yet the vulnerability claim has a concrete empirical basis, namely the emotional well-being of a child. While attitudinal or representational elements cannot be discarded fully (meaning that in its extreme form the call for child-centered and affective or care-orientated parenting is moral in composition: a Good parent aims to optimize his or her child's emotional well-being) the successful "empirics" exhibited by having a happy child is likely a strong counter argument to this demand. Indeed, the appeal of the "Good parent argument" diminished as the child grew older. This may well be understood from what we just discussed. After all, in very young infants there is no empirical base from which one can measure the "quality of parenting" so to say. Very young infants, say 1 or 2 years of age, are rather "global" and lack distinctiveness hence making them unfit for such purposes. It seems that these parents in particular are sensitive to the Good parent argument, while as we discussed in the previous section parents of older children appear to shrug their shoulders so to say as they can rely on the empirics of their concrete child.

Deafness as an ethnic or cultural trait

We have shown that DC-ID portrays deafness as a culturally relevant trait. Deviance from the Deaf culture path as such becomes synonymous to a rather questionable moral attitude, perhaps of intolerance even. In the previous paragraph we suggested that the acceptance discourse must assume an indisputable "reality" of deaf children, a "natural state". The cultural argument must reason along somewhat similar lines. Modell for example, has illustrated how the trans-racial adoption debate in the United States has taken a similar turn as she speaks of the rising ideology of "biological destiny" – an issue on which we will elaborate in chapter seven (Modell 1997; Skolnick 1998).

Indeed, the DC-ID argument provides a detailed prescription on which ingredients exactly constitute this "unique" cultural identity. The assumption appears to rely strongly

on the understood "reality" of adult deaf people they are launched as the "reality" benchmark for young deaf children

> Why not help them meet deaf people since it is the world they are destined to live in? (Lane 1992)

While this is rather common in the case of minority debates, most of these debates evolve around biological parent-child relationships and therefore must also have to do with the right of parents to raise their children according to the preferences or life plans that they hold Yet this is not the case for most deaf children and as such we do not directly see a stringent reason to assume that this must be the case vis-a-vis deafness Rather a pragmatic line of reasoning seems more sensible *if* adult deaf people unanimously represent a homogenous set of preferences and if these preferences were developed positively (i e the choice was made independent of context or available choices) it may be argued that these preferences are likely to become the reality of deaf children as well This could translate to a moral duty to endorse the Deaf culture prescriptions, yet it does hinge on specific premises

Premises of the cultural argument

- Deaf culture represents a homogenous set of preferences
- Deaf culture is the unanimous preference of adult deaf people
- Deaf culture preference represents a positive choice

It appeared that parents targeted precisely these premises in their reply Parents questioned if the "state" of deaf adults was indeed undisputed

> *F There are 10 000 deaf people [in the Netherlands-ccw] so there are 10 000 stories (C5a)*

Parents assumed that the "hard line" Deaf culture arguments found in the discourse of some Deaf adults does not imply that *all* deaf people perceive things that way They substantiated this view with narratives of deaf acquaintances

> *M I know people with their own business rather cultivated deaf people But they were expelled as well, jealousy They have said to me we do not want to be part of that clique we do not feel at home there and the other way around These deaf people do not feel at home there (C10ab)*

> ***M: There is this deaf boy at his school, he has two deaf parents. They both attended IvD and learned to speak and they want their own son to be raised orally as well. So you would think: a deaf son of deaf parents, he surely attends deaf school. But he does not; he attends a hard of hearing school. That is a confirmation of our...eh...that it can be different. (C14b, 3 years)***

M I know quite a few deaf people that do not fit the picture [of Deaf culture -ccw] But the thing is that no one is aware of them since they are dissolved in society (CO3)

M There is another world, for deaf people too I know some of them (C9a)

M I spoke to this deaf woman about Sign language and she wasn't for it at all She argued that you really need spoken language (C6)

The central argument however, homed-in on the assumption of "positive-choice" (Lane 1997) Parents discarded the view that Deaf adults positively chose for an existence amongst Deaf peers However rich and vibrant Deaf culture may have turned out to be, the adults that constitute it today never had a choice really, so parents reasoned Rather they were brought up in a system that socialized them to be Deaf

F It is constructed [Deaf culture identity-ccw] at deaf schools I mean they meet each other there and even after they leave high school they continue to look each other up (C6)

Parents found this stigmatizing and patronizing

M Yes, it was all about being deaf and your mother language is Sign language That was really a hype back then and it still is a little
I What did you think about that?
M I thought it was terribly patronizing (CO3)

Alternatively parents viewed the route to Deaf culture as a "retreat", because of a lack of skills to engage in hearing society

M They are deaf people who have missed the boat These are deaf people that did not succeed to master spoken language and did not succeed in finding a reasonable job They sought each other out of loneliness It is these frustrated deaf adults that you meet all the time (CO3)

F The sad thing is that it can be the most reasonable route [Deaf culture-ccw] depending on personal circumstances Like, if you have minimal speech skills and you are perhaps a little closed in social terms it can be very hard [to function in hearing society-ccw] and Deaf culture and Sign language may be the best way (C9a)

F: It is the negative deaf people who speak up really. (C14b, 3 years)

By portraying Deaf culture as an "exit option" the moral credibility of the (pragmatic) cultural argument is destabilized If Deaf people formed their unique identity by virtue of long standing segregation or as a response to a failure to integrate into hearing society, the value of these narratives is placed in a different background A parallel may be drawn here to the case of the early twentieth century leper colonies Lepers were also isolated from family and mainstream community up to the 1960s, often from early childhood

onwards. After quarantine was lifted in 1969 many adult lepers remained in their secluded colonies, such as the famous Kalaupapa colony on the Hawaiian island of Molokai (Silla 1998). Silla has described how "distinct identities" came into place in leper colonies, which may explain why some lepers chose to remain in their secluded community when they were granted the freedom to leave after microbiologist found that isolation was an epidemiological *faux pas*. Much as has been stated about Deaf culture, Silla does not portray the leper communities as pitiable victims but rather as members of a "vibrant culture". If however, distinct identities and a vibrant culture are primarily the result of forced and wrongful segregation (based on wrongful scientific premises in the case of lepers) starting from a very young age, it appears rather paradoxical to uphold the outcome of that segregation (a distinct identity and culture) as moral imperative for new generations of deaf children.

Indeed, some parents expressed this perspective. Much the same as Silla respects the choice of adult lepers to remain in their colonies, parents sympathized with deaf adults who claimed not to option for a "magic cure" for deafness if it were available.

> *M. You cannot take that away from them You will destroy them if you do. (CO3)*

But parents also felt that it was wrongful to extend such a preference to their young children.

> ***M: Well, but they are adults...if you are grown up and you have developed your own identity and personality and it circles around deafness. If in such a circumstance you would suddenly hear again, I think you would no longer know where you stand and whom you are and what to do. But a child is a different story. (C14b, 3 years)***

It therefore seems that parents did not view Deaf adults' preference for Deaf culture as a positive choice, but rather as an end-result of where life took them. Once this place is reached in adulthood and once firm identities are formed around it, the question of change seems rather inappropriate or even impolite. Yet this inappropriateness is not applicable to young generations of deaf children, parents seemed to maintain.

An alternative explanation for Deaf culture advocacy is that we ought to see it in terms of the extended pragmatic argument that we discussed in the previous paragraphs: aiming for mainstream participation may be depicted as "unreasonable" from a psycho-social perspective, yet we showed that parents wished this to be determined contextually rather than being a indisputable axiom. Furthermore, parents sometimes questioned the assumed socio-emotional benefits of Deaf culture.

> *F: I am sure that they are not happy about that [social isolation-ccw]. (C5a)*

> *F: I would not want to bet on that, they will have to show me first, that all those children raised in Sign will be happy when 15 or 16. That is not my impression. (C9a)*

They also refuted the inevitability of emotional injury if life plans were set outside the Deaf community, based on real-life examples.

> *F Look at John [deaf adult-ccw], he is completely deaf and makes a rather happy impression. He does sign but does nót choose for that so explicitly. [...] The suggestion is made so often that people will be happy in the Deaf world, with their own language. If you do not do that and do not use sign, you categorically cannot be happy (C9a)*

One step further is that Deaf culture may be perceived in "strategic terms" primarily, an issue on which we will elaborate in more detail in chapter seven (Spivak 1990; Taylor 1994a). Deaf culture may be perceived as the most efficient political strategy to safeguard the interests of deaf people in our prejudiced society. A secluded Deaf culture may function as a "mini-society" where stigma can be fenced-off and autonomy can flourish, if at least society assumes responsibility towards such a world (Wever 1997). Indeed some parents came to see the Deaf culture claims as strategic-political in origin. Yet the logic and validity of this strategy was questioned.

> *M· It would be ideal if [hearing-ccw] schools taught Sign language at grade school level. [...] If they did we would look at deafness completely different in 20 years time*
> *F. Yes, but is that a realizable goal? (C6)*

The "militant" Deaf-pride attitude was criticized along the lines of Goffman (1963): it was felt first and foremost to call more than desirable attention to specialness and lead to more than desirable isolation (Wever 1997; Frank 1991).

> *I· Do you think that that approach [about a deaf girl who fought her way to college with court cases-ccw] benefits the deaf?*
> *F. To the contrary! It makes them a little separate group again. (C7a)*

> *M. They keep drawing attention to deafness, but that works counterproductive. (C6)*

Some parents felt that a strategic-political route may eventually help the deaf from a societal perspective, but is likely to harm them socially:

> *F· I have worked in human resources for some time I know people who battled a dispute with their employer through legal channels. Well, they often win But it leads to a disturbed relation on the work floor And when they apply for a next job, the employer will think "a court case huh? I am not going to take this person!" (C7a)*

Parents recognized and debunked deaf ideology and came to see DC-ID as political movement originating in and benefiting the adult Deaf population primarily.

> *M: The adult Deaf population benefits if resources are spend at subtitling and Sign translators, so that explains things perhaps. (C9a)*

F: We feel that the emancipation of Sign language almost obstructs that we teach deaf children decent speech skills, because they "do not have to speak" right? (C11)

Parents seemed to sense that deaf schools adopted their DC-ID advocacy too enthusiastically and too recklessly and did so at least in part as a response to the fierce rejection of the traditional oral-aural programs by the adult Deaf community.

M: At [Sign oriented deaf] school things were really fuzzy. They were all into...well Sign language was on the rise. And a lot of deaf people revolting against their own upbringing. (CO3)

M: In the beginning I did not understand it at all. Now I see it as...well it is like the feminist movement, like those "dolle Mina's" going over the edge only to reach a balance much later. The Deaf world is like that too. [...] It is all much too radical. [...] I think they will become subtler once they have attained a position, just like women did. But right now they cannot afford this.
I: Why not?
M: Because they will never reach the goals they aspire. You have to go over the edge to get to a normal situation. (C12ab)

Many parents felt that in this political climate the focus on Sign language and Deaf culture had become too radical and went too far: it had become a "purpose in itself" and as such lost touch with the interests of deaf children that it ought to seek (C6).

M: I think they carried the whole thing [Sign language-ccw] too far. It is like businesses, once they have an idea they stick to it and that is it, everything has to give way. (CO7)

M: Sign language has become a business, a business for all those involved. And it sells well: the media loves it. (CO3)

F: At a certain moment it appeared that they took the bilingual issue out of proportion. [...] To suddenly madly do everything in Sign language is not necessary. They should see bilingualism in such a way that they dó master spoken Dutch well. The scary thing about how things are going now is that they go from one extreme to the other in a flicker! (C15)

F: The recognition of Sign language as his first language...but you have to establish that he will have to function in hearing society. So it is crucial that his school prepares him for society as good as possible. We almost feel that the emancipation of Sign language obstructs this, that the deaf do not learn to speak because they do not have to speak right? "We have our own culture"...that may be so. But if it is your aim to place your child in society by optimizing Sign language, then speech education should be a part of it. Crucial even to better his chances in the hearing world. This is the critique many parents have. Too much gymnastics, too little speech education, a strange balance really. (C11)

Parents thus felt that it was time to rethink the deaf curriculum and if deaf schools failed to do so, they needed to take that responsibility single-handedly. As such, parents often characterized themselves as "self-willed" (Isarin 2002).

> *M: Once we set out our course, others were no longer able to influence us. We became self-willed parents, we arranged things ourselves (CO3)*

> *M: I have become convinced that you need to be self-willed. If you do not, you will regret it later. You will regret that you resigned to what they [experts-ccw] say is best for him. (CO1)*

This is a bumpy road that requires energy and constant creativity, but the only route that "can lead to the development of a new paradigm, which is so much needed" (CO1).

In sum, we have described how parents identified the "ideas" of DC-ID and formulated critique against its premises. Parents experienced that the identity prescriptions of DC-ID were at least to some degree arbitrary and felt that conforming to them represents a resigned attitude. Parents felt that the extended pragmatic claim that deviating from DC-ID prescriptions is "unreasonable" in the context of deaf children was invalid, based on their experiences with their older deaf child. Regarding the cultural claim, parents questioned if Deaf culture was indeed the unanimous choice of all deaf individuals. Furthermore, parents had reservations about the suggestion of "positive choice". Rather parents believed that deaf adults were wrongfully socialized into Deaf culture or retreated into it as the result of a lack of skills to participate in mainstream society. As such parents felt that it was inappropriate to a priori extend the prescriptions of Deaf culture to their young deaf children. Finally, some parents viewed Deaf culture as a strategic-political avenue that benefited the adult Deaf mostly, though they questioned the reason behind this strategy as they felt it stood the risk of being counterproductive. Parents felt that deaf schools' radical advocacy of Sign language and Deaf culture should at least partially be viewed as a response of the outcries of the adult Deaf population. As such deaf schools' policy had become too radical parents felt and had lost touch with the best-interest of the children that they ought to serve first and foremost. As such parents felt it was their task to rethink the deaf curriculum in a rather self-willed manner.

Failed promises and mounting liabilities

In chapter four we showed that deaf ecology sometimes suggested that the bilingual approach represents a "win-win" situation, resolving the tension between gardening and guardian values to some extent, dismissing concerns over spoken language acquirement. Yet the bilingual promise is empirical by nature, which implies that in time parents can experience if it is actually being met: as the child grows older he or she becomes "living empirical material" for the claims of bilingualism. Indeed this turned out to be a

paramount experience for many parents who initially optioned for an exclusive sign-language environment.

Parents learned that "they were sent off empty handed" (de Wagt 2001; Bertling 1998).

> *M: I soon became aware of the fact that a lot of things [claimed by social workers-ccw] were absolutely untrue. (CO7)*

One parent for example, experienced that her child had continuous difficulty with elementary arithmetic tasks. The schools attitude had been unwound, claiming that the skill would surface "by itself". Yet in time this argument did not work any longer.

> *M: They just said: just wait, it will be all right. Well I don't believe that anymore Sure, it will be all right! He is 8 and still can't do it' (CO1)*

Another parent dyad had enrolled their child at a signing school for the deaf, yet navigated on the bilingual promise casu quo had expected that spoken language would develop in spite of this choice (CO3). Eventually this proved not to be the case.

> *M: Because he was six and he did not speak. "Book" he would say. That was the only thing he said. [...]*
> *I· How old was he when you made the balance?*
> *M. I think 4 or 5 years when we realized that things were going terribly wrong. (CO3)*

This was a turning point experience, as these parents relocated across the country to enroll their child at IvD's oral school for the deaf in an attempt to "repair" the damage so to say. Very few parents took such drastic measures, yet many others shared the sentiment.

> *M: That is the draw back of Sign language. Learning to speak is so hard for deaf children. I never realized that it was such a handicap for them (CO3)*

> *F: We have really become focused on his speech development, his writing. He does so little with it (C11)*

In hindsight parents disclosed that they may have decided differently if they knew then what they did now.

> *M: If I knew then what I know now...I would have enrolled her at IvD [oral school for the deaf-ccw] (C7a)*

Many parents thus learned through experience how inappropriate a one-sided Sign language approach can be in terms of realizing the skills required to engage in mainstream society in both social and societal terms. Yet as one parent said, the tragedy

about this is that this experience-based conclusion will often come "too late" (CO3) Though one parent succeeded to reverse misfortune (CO3), others concluded that there was no way back once a child failed to speak by school going age

In sum, parents of older children came to experience the fallacy of the bilingual promise first-hand This was most obvious in the case of spoken language acquisition, which failed to develop in several Sign language schooled children For many parents this was a landmark experience Some changed schools in an attempt to realize spoken language after all Yet others felt that by the time they came to realize the deficiencies of an exclusive Sign language approach, it was unfortunately too late to reverse the situation

Fencing off the authority claim

We previously described that deaf ecology sometimes actively discouraged parental involvement in the upbringing of their deaf child by minimizing the value that parents have in this context Parents were depicted as laymen, as lacking the expertise to make sound decisions for their children Yet the assumed incompetence was sometimes also depicted as rather unbridgeable since it was linked to parents' hearing status really by virtue of being "hearing" parents were sentenced to the status of "outsider" so to say, which supposedly limited their ability to empathize with the life of a deaf individual (Wever 1997) Moreover, combined with the fact that parents are not native signers, it was assumed that this limited parents' ability to provide for their child in socio-emotional terms All in all this induced a battle of tutorship

It emerged that the experience of being labeled as being of no support or use to one's own child was counteracted by many parents (Voysey 1975, Philp 1982) Parents generally resented the idea that they would not be able to provide for their deaf child as they would of any other Rather than being frozen by this preconceived notion, parents generally actively resisted it and looked for ways of "proving it wrong" so to say The experience of being disregarded by deaf ecology thus appeared to prompt many parents to attempt to regain significance Indeed, regaining significance, power or control is one of the central themes in the literature on parents of children with a disability (Simons 1987) Information gathering, rationalization of emotions (Boyd 1997) and Sign language, common to many parents in the early days of their child's deafness, are perhaps some of the most vivid early examples of such an attempt Yet these early attempts sanction deaf ecology discourse really It thus seemed that at least initially, parents attempted to regain significance *within* the moral framework that they encounter at deaf institutes As institutes present themselves as a nursery garden of fluent Sign language, parents throw themselves at courses in Sign Because schools confront parents with established knowledge on the emotional needs of a deaf child, parents buy books on child psychology Yet self-willed experienced parents that contemplate to dissent from the deaf ecology discourse need to tackle the authority claim more fundamentally

Particularly where it concerned the emotional care for their child, parents turned down interference by deaf ecology By doing so parents seemed to reject the underlying notion that schools needed to take care of a deaf child's emotional life by virtue of parents' failure to achieve this

> *F They had to do all kinds of exercises [at deaf school-ccw] to experience the feeling of happiness and sadness At a certain moment we said we do not care about those lessons just offer him something else*
> *M He knows that [emotions-ccw]*
> *F We do not want that we are against it (C5a)*

Yet the resistance was not restricted to the most basic emotional care It seemed that parents insisted that they had considerably more to give to their child beyond love and tenderness Perhaps this can be encapsulated under the denominators "guardianship" and "tutorship" parents felt that they had a significant role in standing by their youngster as he or she was growing up, serving him or her with warmth and protection when needed and providing him or her with valuable lessons of life Perhaps this can explain why some parents felt resistance against the suggestion that their signing child would soon have little to learn from his or her parents as the result of superior signing skills of the former

> *M They told us that there would come a time when we would have to learn Sign from her rather than the other way around That is gibberish! We did not want that [ ] I wanted to teach him everything not learn from him That is when I started to visit Deaf clubs [to improve signing skills - ccw] [ ] I wanted to teach him everything not learn from him (C5a)*

It also appeared that taking seat in the schools' parent-counsel or participating in interest groups empowered parents against deaf ecology

> *M We visited all the institutions over and over again lobbying for parental participation and promoting the role of parents It was not easy it was a difficult road indeed (C1a)*

While we did not compare our respondents with parents of hearing children, the level of involvement in the education of their children was significant indeed over half of our respondents were active at the local deaf school level or in regional or national deaf advocacy Five parents were parent-council members at their local deaf school (C1a, C6, C15, CO3, CO7) One parents was active in a regional chapter of the national disability council (CO2) Three parents were active contributors to the federation of parents of deaf children (FODOK) (C11, C13, CO1) while another threesome was active in the NVVS, the National Federation for the Hard of Hearing (C5a, C7a, C9a)

There may be some parents who are unable to regain parental significance Though none of our respondents fitted this picture, all said to know parents who lacked "the edge" to

make the necessary investments to re-acquire parental significance, hence had little other choice but "stoic acceptance" (C13, C5a).

> *F: There are of course quite a few parents who say: this is it, this is how he or she will grow old (C9a)*

For these parents the deaf institutes' potential for parental replacement may be experienced as a relief.

In sum, many parents engaged in a battle over tutorship. While during early childhood they did so mostly in consent with deaf school discourse, parents of older children formulated more fundamental critique. Parents dismissed the suggestion that only the deaf school environment could provide a nourishing environment in socio-emotional terms. Parents also reproached the notion that they would not be able to fulfill the parental role in terms of providing their child with the valuable lessons of life so to say. A more concrete avenue that many parents took, was active participation in advocacy organizations. A surprising number of parents was active in such organizations. Finally we suggested that some parents may lack the resources to engage in the way described and may as such resign to the deaf school protocol.

The new parental perspective

In the previous sections we discussed how parents positioned themselves vis-à-vis the claims of the DC-ID discourse. Generic vulnerability was discarded as stigmatizing and uncalled for given the context of their deaf child. Parents generally felt that their child's characteristics allowed considerably more room for challenge, given his or her scope of resilience. Parents also identified the "identity" and "cultural" arguments as "ideas" and criticized the premises of these claims. Finally, parents experienced the fallacy of the bilingual thesis and dismissed the authority claim.

As parents organized their opposition against the DC-ID discourse, this granted the space for a new perspective to arise. While parents of young deaf children were inclined to value socio-emotional aspects of their young most highly (chapter four) we found that this perspective did not persist, at least not one-sidedly. The new keywords in parents' narratives were "self-reliance" and "independence". These values were aimed at the future: parents hoped that their deaf child would be able to stand on his or her own feet, independent of parents' support.

> *M: Yes you just have to, at least I do, raise your children to independence. (CO5b)*

> ***I: Do you have a concrete idea about the future, like hopefully it will be like such or so?***

> ***M: Well, I have a wish but it is the same wish I have for all my children. That they are able to stand on their own feet and have jobs and that they enjoy an education that suits them and, yes, that they can handle. (C13, 4 years)***

Yet parents also aimed to prepare their child for self-reliance *independent* of "special" social measures or services, hence circumventing the "social workplace" so to say.

> *F Sure he can go to some social workplace, shovel around, meet a deaf girl and get deaf children I know that story by heart (C5a)*

In this context the Deaf community was clearly not perceived as an advantageous outlook

> *M How I would feel if she retreated in the Deaf community? Well that brings you back to your parental task now doesn't it? I would argue "sure, but you have to engage in society sometime, you must be able to work" (C6)*

Deaf culture was seen as rather dependent on the benevolence of hearing society. Some parents touched upon the possibility of social events that would magnify their child's vulnerability to illustrate and justify the perceived need for independence and self-reliance beyond the context of Deaf culture.

> *M As long as the economy is doing well, things will be all right [ ] But it is a matter of survival That was one of my motives too [ ] He will have to be able to be self-reliant, in crisis situations, yes Because it may not be like it is now 15 or 20 years down the road Right? (CO3)*

> *M I have thought about it sometimes, like imagine if this or that happens Disaster scenarios really [ ] If something happens to me, eh, I do not want to raise him in such a way that he will not be able to get over it [ ] I won't help him if he dies with me No, he has to be able to continue his life the way it is now (CO5b)*

> *M Of course they can live nicely in the Deaf community like in the United States But that really is an option for the rich only (CO3)*

Deaf culture was perceived as a "safe haven": as a place of refuge for those who failed to find a secure spot in society. As such it was seen at odds with what parents aimed for in this phase

> *M How I would feel if she would choose to submerge in the Deaf world? A little like I failed I think (C7a)*

> *M I can imagine it being very safe for him A very non-threatening environment But not more than that (CO5b)*

> *M: I can imagine that that [Deaf world] is very comfortable, real safe and protected, but I do not think that is real life And I think he has to experience that and can then make his own choices. That is what we need to prepare him for. (CO5b)*

While parents upheld the child's right to decide to engage in Deaf culture or not, they also felt that a choice could never be made if certain skills failed to develop. Parents perceived their task as one in which they needed to provide the means for a child to be able to make a decision later on.

> *F: I compare it with religion sometimes. Some parents give their children all the things that belong to religion. Yet the factual decision is up to the child him or herself. Like: "I understand what it is about now and now I will decide" [...] You try to create the conditions (C5a)*

To be able to attain independence in this sense, parents upheld the centrality of specific skills and achievements.

Skills related to independence
- Spoken language skills
    - Facilitates educational window of opportunities
    - Facilitates societal window of opportunities
    - Facilitates social window of opportunities
- Cognitive and educational achievement
    - Facilitates educational window of opportunities
    - Facilitates societal window of opportunities
- Familiarity with and social skills in hearing society
    - Facilitates societal window of opportunities
    - Facilitates social window of opportunities
    - Beneficial to resilience

Spoken language acquisition was one such a skill. A decent education was a highly appreciated achievement. Becoming familiar and comfortable with hearing society was another skill that was valued. As a result parents increasingly investigated means to realize these values. We will discuss these topics separately.

Spoken language skills

To be able to make a choice, parents seemed to feel that substantial investments in spoken language skills is called for, even if this goes to the avail of signing skills: "Sign they can always learn" one (Sign proficient) parent commented (CO3). Even parents who had initially invested deeply in Sign language came to value the mastery of spoken language skills.

> *F For me [the decision for Sign language] is without any doubt. But as my wife says, and that goes for me just as well. we always found it important that...we feel that it is a*

liability of the education [at Sign orientated schools-ccw] that next to Sign language, speech training is important you know, both should be stressed. (C11)

While Sign language provided a "close-fit" with parents' values during the early years of their child's life, spoken language skills were congruent with the value of self-reliance that appeared after time.

M: It is for the future. Sure Sign language is fine and we have taken all the courses offered. But once she is grown up, she will have to be able to get along. [...] We chose for Sign language positively to get contact with her, faster. But in the back of our minds we thought that she needed to learn to speak when older. (C2b, 5 years)

Spoken language skills were highly appreciated for a number of specific reasons, all of which can be related to the value of self-reliance.

M: It is his life you know. If he just wants to use sign, that is his choice He can choose But we wanted him to learn to speak. We wanted to give him that opportunity (CO3)

M: Look, if one would not have the capacity, psychologically or neurologically, to speak it would be a different story all together But I feel it is an opportunity that he does have at this point and as such one should offer it to him You have to offer it to him, to do things as broad as possible If in the future he would come to say "it has been enough, you may want that for me but I am deaf and I want recognition for that and I will seek that in the Deaf community" that is fine. It's fine if he would seek that security there But it is not something which I, from which we depart a priori. (CO5b)

First, some proficiency of speech was perceived of as a prerequisite to facilitate the educational window of opportunity. Secondly spoken language skills were seen as a requirement to allow a deaf child to socialize in hearing society. With this parents did not refer to participating in social events per se. Rather, mastery of some spoken language skills were believed to increase "social mobility" so to say. To be able to get around in hearing society, spoken language skills are rather convenient.

M: First Sign language, then written Dutch And for those who can, speech Because it makes things so much more easier if you can ásk for a bus ticket Much easier than if you have to write it down because people can't understand you (CO1)

F: Sign language is fine in the Deaf world. OK, they understand it there, but if she wants to go to the store next door it will be of little use to her. (C2b, 5 years)

M: I think that he has to keep using sign. I support that completely. That is his first language so to say. [...] But speech for the outside world, [to prevent] exclusion. Not in the family, we sign with him...but in the outside world, you cannot expect that [Sign proficiency] from them. They will never learn. (C14b, 3 years)

F: Look, it is real simple. We know these deaf people and if you meet them in town and you say something to them, they will answer [but you cannot decipher it-ccw]. If they cannot speak or cannot speak intelligibly, communication is doomed to end. You will wave to them one last time, and that is it. (C9a)

Other parents felt that hearing society was an inescapable reality with which their child would have to deal. Some mastery of spoken language would facilitate this process.

I: You speak about choosing to be deaf. What does that mean in your vision if she chooses to be deaf?
M. That she enters the Deaf world. That brings you back to your parental role, you think "yes, but my child you have to deal with the larger world when you are grown up!" (C6)

F: Our view has always been that, whether you accept deafness or not, if you want to get along in society it is awfully useful if one is intelligible, if one can communicate well. Now that may be Sign language but nine out of ten times when people communicate it will be through words and not Sign language. (C15)

F: You must realize that he will have to function in society so deaf schools should prepare them for that. (C11)

Yet a few parents also valued the availability of the hearing world in social terms, since they felt this would enlarge their child's social reservoir.

F: If they are all into Sign language, they will not be able [to communicate with hearing people - ccw]. That is the problem. While if they integrate into normal society, they will be able to deal with those people too. [...] I have always found that strange, people who out of belief join the club. You'll be stuck to such a small community...(C3b)

F: The Deaf world may be able to keep injury away But we have always said like, it is like a post-stamp and this is the Netherlands. (C5a)

M: Well, it is like a gnome-village isn't it [Deaf culture-ccw]. That is not fun for anyone of course. (CO1)

M: The Deaf community is limited isn't it? It is not an enriching experience. (CO3)

Thirdly spoken language skills were appreciated to improve societal opportunities in terms of employability and career. Parents felt that proficiency in spoken language was valuable in terms of facilitating a deaf child's societal window of opportunity.

F: We always claimed that while he may be deaf - that is indisputable - we are going to try to give him a place in society nonetheless. And that implies that you should not aim at Deaf culture exclusively. (C5a)

Failure to speak was perceived by some as a portent of a bleak societal outlook. A deaf man who cannot speak or cannot speak intelligibly is unlikely to be successful on the work floor, some parents seemed to reason.

> *M: Which boss would want a signing deaf employee? Surely they would prefer someone who can speak. If she wants to sign, that is fine with me, but career wise she'd better learn to speak. You have to 'kick' them into a career really. (CO3)*

Failure to obtain a job implies dependence in the form of social security or a social workplace and thus negatively influences independence and self-reliance, values that parents held highly.

While a full-time Sign language translator may be depicted as a solution to all of these issues, some parents were critical of this. Translators were perceived as incompatible with normal socializing behavior.

> *M: I think it is a disaster. And you won't get a translator because there are too few around or they say that they need them for other activities. We did think about it. But then there will always be a translator in between. And remember she is heading into her adolescence; imagine a translator in that context! (CO2)*

Additionally parents resented how Sign translators make deaf individuals dependent on others physically.

> *M: They will become like the princes of orange, right.*
> *I: Can you explain?*
> *M: Well, with a "bodyguard" hobbling behind them everywhere. (CO3)*

A few parents felt the Sign translator option made their child highly dependable of a society willing to finance and realize such resources, an issue that has also been critically addressed by Reinders in the context of the position of the mentally disabled in liberal society (Reinders 2000). Surely, making translators available for educational and social purposes is an expensive option. Some parents were skeptic about society's readiness to cover such costs, if not now than in the future.

> *M: So, when Sign language is recognized as an official language everyone has the right to a translator That is unaffordable. (CO3)*

Indeed, even today Sign language translators are neither limitless in supply nor financed unboundedly.

Educational achievement

Parents appeared to tolerate a deficient grade school career to some degree, mostly to facilitate the emotional well-being of their child. As we discussed in chapter four, a

signing deaf school was sometimes considered the most fit for such objectives. Yet parents seemed much less willing to compromise high school education. A compromised high school career appeared to be perceived as a serious threat to safeguarding a child's window of opportunity in adult life

> *F Solid self-image yes, but after that [childhood-ccw] I hope that he will be able to make the jump (C11)*

As high school approached, parents became more and more critical of the low-challenging atmosphere at deaf school. Parents sometimes felt that deafness was used as an excuse for low educational standards for too long.

> *F Maybe they have drawn a link with deafness for too long They hide behind the excuse of deafness*
> *I At school?*
> *F At school or wherever Look, they say all to easily 'it is because of her deafness" (C15)*

As a result, parents started to draw out more demanding educational plans.

> *M I hope she will be one of those 7% going to higher education I try to push her for it She's got the brains for it, so that makes me feel like 'we'll have to get it out" [ ]*
> *F Secondary education is getting close and [you notice] that more parents are talking, like "guys, what are you [deaf school] going to do with my child"*
> *M It is like, you think, you want the best for your child in the future or not? (C15)*

As an example, many parents who had initially enrolled their child in a signing deaf school considered a transfer to IvD or mainstream education (CO3, C5a, C9a, C10ab, CO7, C11, C12ab, C15). These were all parents of older (≥ 8 years at time of interview) children Two children were actually transferred to IvD (CO3 and C9a) and three were actually mainstreamed (C9a, C5a and C10ab).

Parents recognized that preparing their child for autonomy would demand more than what was offered by the deaf school curriculum The fact that a deaf person has to work harder to achieve similar results as a hearing child was acknowledged as a given and certainly not denied

> *F There is this theater next week*
> *M But he does not know at what time*
> *F He missed that, it slipped by So we said to him "what a jerk you are"! He knows that we feel that way It is unacceptable If things are discussed and you feel that you missed something, even if it is only a feeling, you go over and ask! Whatever it is You make sure that you get the information*
> *M You won't get anywhere without asking*
> *F If you do not do that, you'll be carried away through the backdoor, everywhere! (C5a)*

As we described earlier in this chapter, parents disagreed with the "over-protective" low-challenging philosophy at deaf schools and felt that their child's resilience allowed a much greater challenge than assumed. Parents looked at a child's limitations on its own merits rather than a priori assuming that a challenge induced by deafness is "overly demanding". A challenge posed due to deafness is not by definition perceived weightier than a challenge posed due to for example a lack of focus, playfulness or a lack of intelligence in an otherwise healthy child. Rather parents scrutinized the specific character of the challenge involved and gauged it against their child capacity and resilience. Still, as we previously showed, some parents felt that dissenting from the deaf school curriculum was too demanding for their deaf youngster. Yet even these parents in principle adhered to the issues discussed here: their choice to keep their child in the deaf school environment was regretted, "we stand with our backs against the wall" one parent said (C7a).

Familiarity with hearing society

In chapter four we argued that some parents valued the secluded deaf school environment, for it keeps potentially harmful stigma away from young deaf children. Yet in time parents revised this view: the protectiveness of deaf school eventually lost its appeal. Parents felt that after the grade school years, it was time for their deaf child to meet the hearing world. Remaining in the sheltered deaf school environment was perceived as a "missed opportunity" to learn to become self-reliant in that world. Familiarizing the deaf child with the hearing world was thus deemed important by most parents and was high on their agenda.

Parents feared that a prolonged deaf school experience itself could predestine for an exclusive Deaf culture existence, through a process of socialization or internalization so to say. Much more so than grade school, parents viewed high school years as rather crucial from a socio-cultural perspective. Indeed in psychosocial literature, identification is a major task during adolescence (Erikson 1975). If the deaf school experience lasted too long, parents feared that their youngsters would silently internalize a "standard" that excludes hearing society from deaf individuals, which would lead them not even to attempt to integrate.

> *M: Look she will be able to choose but I think that if you grow up in the Deaf world there is no choice really If you are there it will be very hard to find another road (C10ab)*

> *M: Look, she has a choice when she is grown up, but I think that if you grow up in the Deaf world exclusively, you cannot really choose, you're stuck there. [...] After the end of the boarding school years, social roles are very fixed you know And they are all confirmed in it so terribly much. (CO1)*

> *M: They are pushed into exclusive Sign language there. (C7a)*

M: I think you have to at some point or another [integrate in hearing society-ccw]. Look, once they attend secondary [deaf] school there aren't so many choices now are there. (CO6b)

Moreover, sensitivity to "ideological identities" is also rather significant during adolescent years and it seems that the way that Deaf identity is promoted in Deaf circles ("Deaf pride") may well conform to such a definition (Scroggs 1988). Parents seemed to sense that boarding high schools for the deaf represent the cradle of Deaf culture, at least of the segregated elements of that culture.

M: You know that there are children who go to residential school because they want to be amongst the deaf, deaf peers I can imagine that, but have serious reservations. So, to say "go ahead" like some parents do, like "if you have such a need for that then go to residential school".. For as far as I can evaluate I think a lot would have to be wrong before I would do that.
I: What other options do you envision?
M: Well, just let the kids come here. We have said it frequently; we live here and can organize camps. Let's invite 10 deaf kids and their families or something like that. You can think up lots of ways. It will take time, but at the end you can make it a part of your life. (CO1)

M: One drawback is that all the activities are based on and are exclusive for deaf children. deaf horseback riding, special such and so for deaf children You create a Deaf world, don't you. (C7a)

Parents also felt that while the protective environment of deaf schools may be able to fence off a stigmatized self-image, it will ultimately boomerang when adolescent deaf school graduates enter hearing society. Elsewhere, we have described this adult experience as harsh and disappointing indeed (van Noort 1999). Parents assumed that a delayed exposure to hearing society would result in more intense shock, which in turn could cause a deaf adolescent to retreat into Deaf culture. As such parents felt that early exposure to hearing society had concrete advantages. It was theorized to reduce shock and thus the chance of retreat into Deaf culture.

M: When they finally left the institute they would notice: "hey nobody understands me and nobody wants me". So my attitude is, she better deal with that early on. (CO2)

F: We really worry about that, like how will he deal when he becomes more aware of his deafness as an adult? How is he going to cope with that? [...] He may have a good time at deaf school now, but once he leaves he'll get a severe blow. (C11)

Moreover parents felt that exposure during childhood years allowed them a better opportunity to gauge and steer a child's response. Furthermore, retreat into Deaf culture as an adolescent was perceived as a one-way street since it shuts the door in terms of

familiarizing oneself with "the numerous rules and conventions" of hearing society (Beck 1996).

> *M We wanted him to be confronted with his deafness And not at age 19 or 20, that he would ride his bike to town one day to get drunk and never come back Now we still have grip on things (CO3)*

In the end parents thus assumed that early exposure to hearing society would decrease the chance that their child would retreat into Deaf culture, something parents wanted to avoid because of the negative impact on a child social and societal window of opportunity. One parent, whom actively engaged her child in hearing society, compared her child's social status to that of an acquainted deaf person who attended deaf school well into his adolescence to conclude:

> *M I think if she would go back to deaf school she would end up being an outsider Now she can have a comfortable and regular life I think [ ] We have this deaf boy in the neighborhood, he used to visit here in the past If you see him now, he will be alone at the swimming pool and riding his bike alone That is not the place I wish for her (C10ab)*

Retreat into Deaf culture as an adolescent was not perceived as beneficial to one's sense of self (CO3). Congruent with Goffman parents seemed to feel that the experience of stigma decreases rather than increases as contact with hearing world advances (Goffman 1963). While initially, the full array of stereotyping is likely to emerge, eventually the degree of stigmatizing may moderate Indeed one older child who resided in a small village was doing remarkably well from a social perspective in spite of only marginal spoken language skills (C3b). Another parent dyad talked about the relatively low stigmatization in the Sint Michielsgestel (IvD) area.

> *M In Brabant (province in which IvD is located-ccw] people are accustomed to deafness*
> *I In this area?*
> *M Yes, because there are so many deaf people around He wasn't stared at anymore [ ] Everyone treated him as a full human being That was a metamorphosis, when he experienced that (CO3)*

As a result parents made an explicit effort to familiarize their child with hearing children and vice versa. One of the most common ways in which this was achieved was through sport clubs (C7a, CO5b, C11).

> *M No, that is why we always sought contact She attended a normal kindergarten [ ] She has her swimming diplomas She attended horseback riding for six months And now she attends the scouts You know, in the past deaf children would enroll at IvD up to 18 years No sports, no contact with parents (CO2)*

Yet educational mainstreaming, other club activities and social events were also seen as superb opportunities to promote this process.

In sum, many parents were concerned over their child's future ability to be self-reliant and independent and from their utterances on this issue it appeared that parents felt that this required the eventual ability to function in mainstream society. Parents feared that a deficient education, underdeveloped oral-aural language skills and inadequate familiarity with hearing society were ominous factors in this context. Regarding the latter it was assumed that a deferred exposure to hearing society could lead to reactive self-withdrawal

Expectations and the risk of failure

From what we described so far it may seem that parents develop a "normalizing" set of expectations after all Indeed in a certain sense they did as their values clearly overlapped with those held by parents of non-disabled children Yet parents did not "expect" that their efforts would culminate in a situation equivalent to that of a non-deaf child Parents did not expect to succeed, at best they *hoped* they would Rather what parents appeared to do is releasing their child from encompassing scripts that a priori exclude "normal" guardian values. They wanted to at least offer their child the opportunity to a normal range of life and believed that much more was possible indeed

> *F We try to give that [the opportunity to function in hearing society-ccw] to her If she ends up not using it, that is too bad At least I provided the opportunity (C15)*

As we argued, DC-ID's extended pragmatic claim on vulnerability becomes solidified and as such essentializes deafness a deaf individual is considered vulnerable, which calls for extraordinary precautions, which in turn will manoeuvre the future of deaf individuals in a very distinctive direction As such we argued that it presets expectations and predetermines "who" a child can become Parents on the other hand, do not consider vulnerability to be a fixed characteristic of a deaf individual and as such often felt that his or her future needed not be confined to the deaf school protocol Personal assessment and intuition as well as concrete examples facilitated this Parents appeared to focus on more or less "successful" deaf individuals as models

> ***I: How well they learn to speak, where they end up socially, do you know that? Did you have that information?***
> ***M: Yes, we know about some...one works at the deaf institute. She is doing an internship...and there is one in Nijmegen who works in the hospital...Most of them end up really well. What is his name again...he did really well. You hear these things in the corridors you know. (C2b, 5 years)***

> *M He [deaf man-ccw] worked at Stanford University but could not deal with the English He never identifies as deaf And I know several other deaf people They are all assimilated in society They forgot their youth, just like we never return to our grade school (CO3)*

These models were used as support for an argument against Deaf ideology rather than functioning as threshold for expectations per se. Successful deaf adults were the real-life examples that were to counter-balance the "cannot do" premise of deaf schools. One parent visited the IvD and was allowed to attend a few classes. In retrospect she feels that she was shown "successful" oral children only, but that did not appear to bother her:

> *M: They showed those that were above average. I think that he [deaf son] can be above average too, so that is what I asked for. I did not have to see what I had already seen at his [Sign oriented] deaf school, I wanted to see something special now. Well, I did. (C12ab)*

Yet parents did not ignore their child's vulnerability as they very much viewed their child as a child who has some distinct characteristics that can push the envelope of resilience. This implies that they recognized both the concern over emotional well-being in general as well as the fact that deafness *can* have specific bearing on this concern. Yet this perspective does not a priori predetermine "who" a deaf individual can become. This is illustrated by the fact that parents did not hold concrete views on their child's future and also seemed conscious of the fact that their hopes of a self-reliant future were rather uncertain.

> *F: I cannot estimate what his future will be like. It is so dependent on local circumstances, for example if society discovers you [as a person with potential-ccw]. If I look back at my own career for example. I did so many things and finally I ended up in a sector I would never have anticipated. That is true for him too. It depends on specific moments, though it will be harder for him. (C5a)*

> *M: I hope she will succeed [to be able to function in hearing society-ccw] but I am not sure. (C7a)*

> *M: I am concerned about his future; I hope he will make it. (CO1)*

> *I: How do you view his future?*
> *M: I really would not dare to say something about that. (CO3)*

In agreement with what Reinders has stated on this topic, parents thus accepted the possibility of failure, which implies an ability to take risks (Reinders 2000). Many parents accepted the possibility that their child would eventually submerge in Deaf culture in spite of their efforts. Yet they seemed to perceive such an event as one out of emotional need rather than a positive choice, as they often fell back to the socio-emotional justifications.

> *M: First thing is that we want her to be happy. Of course, you stimulate her in a specific direction. That is logical. But if she is comfortable and happy and she is around good people, that is fine with me. It would not trouble me. (C10ab)*

> *M: I just want him to be happy, in which world does not matter to me. (C12ab)*

Given the views of the Deaf community on issues such as spoken language skills and mainstreaming, parents sometimes feared that their child would blame them for their decisions if he or she would fail to find a place in hearing society and would retreat into Deaf culture

> *M I am not scared of that But he still has to go through his adolescence He will likely become reproachful at some point that is rather logical (CO5b)*

One interesting finding in this context is that a few respondents (C5a, CO1, CO7) kept diaries in which they recorded their experiences Almost all parents stated that they desired a copy of the study interview, so they could explain to their child why they decided the way they did

> *M Well, we wrote several things down on paper I write everyday much more than is needed from a formal position The idea is that he can read it when grown up (CO1)*

In sum we feel it is unfounded to judge parents' new attitude as proving the thesis of normalizing expectations (chapter four) right after all Rather parents rejected the other extreme they discarded an encompassing discourse that deprived their child from "normal" values such as self-reliance and independence categorically

Specific issues, cases and controls

Indeed as we anticipated in the introduction of this chapter, the vast majority of utterances in this section were by more experienced parents, defined as parents with a deaf child of at least 8 years of age Case-control status did not seem to be an issue here both contributed significantly Regarding the regional factor that we identified in the previous section, we generally found a predominance of parents residing in the northern and western regions of the Netherlands, though those residing in the south were rather well represented as well The overrepresentation of the western and northern regions was most outspoken in the sections on "debunking Deaf ideology", "failed promises" and "fencing off the authority claim" all excerpts were by parents whose child attended school in these regions (though CO3 had recently moved to the southern province of Brabant) This seems to suggest that the "pragmatic" issue of vulnerability is an issue for many parents regardless of school of attendance all parents will have to formulate an opinion on their child's potential to be challenged and his or her range of resilience to deal with such challenge The "moral" or foundational ingredients of DC-ID however are rather exclusive to the northern and western regions of the Netherlands This finding is in accordance with the findings in the previous section and supports the thesis that deaf schools in these regions are particularly strong advocates of an encompassing and essentializing discourse

Conclusions

In sum, parents come to question the essentialist discourse with which they are confronted. They revolt against the implication that their child is "different" in an essential way and revolt against the "traditional imprisonment" that is suggested by this discourse. Rather parents conceive of their child as very much related to them in emotional terms, a condition they wish to maintain in the future. Ideologically, parents appear not so much to reject Deaf culture and Deaf identity, but rather support liberal notions of individuality in which social identity is more or less subordinated to individual choice, at least if it does not yield considerable liabilities. By de-essentializing the ideological Deaf culturalist argument, parents come to argue on pragmatic grounds mostly. Once the destination of a deaf child towards Deaf culture is cut short at its ideological root, thus once they come to the conclusion that it is *not* morally wrong to question the demands made through this discourse or realize that choices made towards a deaf child are about more than "birth rights" only, parents focus on the pragmatic premises of Deaf culturalism. What pragmatic truth does the ideological discourse allude to, why do they insist on Sign as a birthright? It is these questions which lead parents to a different panorama altogether, a panorama of more concrete concerns and goals, a setting in which *debate* is much more called for than DC-ID seems to suggest.

DISCUSSION

Parents of a deaf child face many decisions in the course of their child's life, in particular during the first few years. While decision-making is never exclusively individual, the degree of involvement of or steering by others will in most instances not be as profound as is the case with a deaf child. As we have illustrated, the new "involuntary" (in the sense that parents have no choice to ignore this environment, they are deeply dependent of it) social context is all but neutral in their posture toward parents. We have attempted to illustrate how this environment plays a crucial role in structuring the decisions parents make. In its core DC-ID remains an essentialist discourse and with time parents come to criticize it, leading to a second and final process of de-essentializing. In time parents thus come to see and experience the Deaf culture story as being ideological and coercive in nature. What we have seen in this chapter is that parents de-essentialized the Deaf culture story, even though not all parents succeeded at this equally successfully. After this process is completed we seem to witness the birth of the "self-willed" parent of which Isarin speaks. This new position can best be described as a rather pragmatic and child-centered attitude. From this point on, parents view stories about their child's best-interest pragmatically foremost. They try to critically evaluate these stories to conclude if and to what extent they will benefit their child, without being too much "disturbed" by their moral connotations. This in turn gives rise to friction between parents and care providers (Isarin 2002). This friction in itself becomes an important factor of influence: it can both repel parents from Deaf discourse as well as contain them. The fact that parents revolt now while they did not earlier may be explained by several factors. Firstly, the growth of experience and knowledge itself may be a factor. Secondly, the developmental stage of their child may be an issue. Most parents who "completed" the process of de-essentializing did not do so until their child had reached an age of about 8 years old. It may be argued that at this age children simply "claim" their own identity, thereby facilitating the rejection of any encompassing script of "whom" there are. A third factor that may explain this is that we found that while the Deaf culture story was rather elementary in the early days, restricting itself to the advocacy of Sign language, it was inclined to become more detailed, encompassing and coercive as time went on. Thus, while the initial main-ingredient of DC-ID was rather congruent with the pragmatic interests of parents in the early days, its "fit" *decreased* in time. The "new" content that DC-ID added to the initial advocacy of Sign language was rather at odds with the interests of parents in this phase.

We have portrayed the character of the deaf school environment, which revealed the central role of secondary evaluative concepts (Hare 1988) such as identity and Deaf culture. Indeed, a crucial step in the process was the essentializing of deafness in a discourse of identity and culture, a process in which deafness becomes not "a trait" of the child but an "essential trait" indeed. As Isarin has clearly discussed in the context of disability, this implies that the central factor is the "what" from which the "who" is

derived (Isarin 2002). It was argued that deaf ecology provides a frame of rational legitimization for many parents. We have also argued that the fact that DC-ID appeals to parents suggests that there must be common preferences involved. The fact that parents were initially sensitive to DC-ID arguments may be explained by several factors. Firstly, this discourse promises an advantageous future outlook for deaf children and parents lack knowledge and experience to draw this in question. Secondly, the "future problems" of the deaf are still rather abstract in this phase. Rather what is concrete for parents in this phase is their concern over their child's well-being and their bonding with their child. Finally, the moral "good parent" argument is rather congruent with parents' state of mind in the early years of parenthood. All of these aspects are convincingly addressed in DC-ID. The preference of some parents of younger children for Deaf discourse may be related to this issue. For parents of young children adherence to DC-ID may indeed be rather attractive. Since they lack a "concrete child", the abstract mode and evaluative nature of DC-ID suits them rather well. Yet, deaf ecology does more than specifying our shared preferences within the context of children. It clearly functions authoritatively: it does not tolerate alternatives very well. Deaf ecology can maintain this authoritative role by the mercy of the profound dependency of parents. This in part explains how the discourse of this ecology rhetorically centers on the parent rather than the individual child: the central question appears to be "are you a good parent" rather than "what is best for your child".

We have illustrated how most parents nonetheless developed strong reservations vis-à-vis DC-ID, became "self-willed" in Isarin's terms (Isarin 2002). While parents recognized that deafness *can* be a source of emotional strain, they felt this was contextual or situational rather than generic or foundational, and did not legitimate the extraordinary precautions advertised by some deaf schools, let alone the predetermined futures implemented through this view. Parents thus felt that it was rather difficult to predict if a specific challenge would imply "over-demanding", rather such a judgment was made pragmatically on an individual and case-to-case basis (Bénard 1998). Some of the reservations that parents held were rational: parents questioned for example if making the deaf dependent on translators for their interaction with hearing people will benefit them most. Other reservations were deeply emotional: for example, parents experience DC-ID as an assault on their role as parent. In time parents experienced the fallacy of the bilingual promise. When a deaf child grows older and parents gain experience, they come to realize first hand that DC-ID is much more fragile than they had thought. Indeed it seems highly contestable if a bilingual approach will yield success in terms of producing "additive bilinguals" in the setting that is provided at this moment (Bertling 1998). Bilingual education programs for Francophone minorities in Canada for example, seek to educate students in their mother tongue (L1), providing the dominant language (L2) as a second language course. It has been shown that these students develop proficiency in both L1 and L2 yet proficiency in L2 is believed to develop through *intense* exposure outside of the school setting. As Laundy has stated "you catch English" (Laundy 1998). It seems unlikely that the deaf will indeed "catch" the dominant language in the way that

hearing bilinguals do. Hence, the current situation in deaf schools may result in a deferral of L2 development. Indeed a few longitudinal studies on spoken language development have shown that deaf children enrolled in a oral setting develop better spoken language skills (yet worse signing skills) as compared to peers in a Sign program (Musselman 1999). While dominant spoken language is commonly perceived by bilingual linguists as a "high vitality" language while the minority language is depicted as a "low vitality" language, in the case of the deaf this remains to be validated It is actually conceivable that spoken language is attributed a "low value" in deaf schools Indeed Tucker has suggested that this is the case (Tucker 1998). A low value attribution to the dominant language may further undermine the acquisition of that language in a bilingual setting.

> Kids who try to speak in deaf schools are ridiculed And the greater their oral success, the more they are criticized (Tucker, 1998)

We also found that most all of our respondents had relatively high educational expectations of their deaf child and also perceived of their child as relatively talented (Bodner 1986). Parents seemed to conclude that the label "deafness" is unable to cover the broad range of children with hearing losses in excess of 95 dB. As such they rejected the "one-size-fits-all" paradigm of deaf schools (Stewart 1998). Factors such as the degree of deafness, the age of onset, etiology, age at diagnosis, additional impairments, amplification history, language history, social experiences, family climate and psychological constitution are some of the many variables which diversify the "deaf" as a group (Paul 1993).

Parents became skeptic of the more profound political premises of DC-ID Most parents rejected these political premises and seemed to aim for "real-world" solutions for their child. Towards the end of grade school parents realize that DC-ID has failed. Parents feel that indeed the well is at risk of running dry Furthermore, they come to perceive of Deaf culture in different terms. Deaf culture is not seen as an "alternative" place for self-fulfillment. Parents see Deaf culture as an "escape" or exit option, which stands diametrically against the value of authenticity and free choice (Taylor 1994a, Fromm 1994) Winzer who writes about the 19th century deaf population indeed supports this perception

> Deaf persons emerging from these institutions thus found "great difficulty in finding employment, in making friends, and in finding entertainment of any kind" (Perry, 1943, p v) [ ] The deaf population's response was to make an effort to equalize the status relationship Not content to remain passive and isolated alongside the structures of an alien society, the deaf population developed its own system Deaf individuals drew together into cohesive groups, and many confined their social relations to other deaf people (Winzer 1993, 222)

Deaf culture was perceived as small in size and opportunities, which parents found restrictive Furthermore, Deaf culture was not perceived as a place where liberal values

such as "self-governance", "individual choice" and "being one's own person" can come into place This is in part the result of the "militant" attitude and the rigid sense of social identity that some Deaf adults supposedly hold

As a result parents came to exhibit a set of values rather similar to those held by parents of non-disabled children This was true for *all* parents We characterized this change as one from a "gardening" perspective to a "guardian" perspective While parents of young children were predominantly concerned about their child's ability to engage in language, the parent-child relationship and his or her immediate well-being, parents of older children became increasingly focused on their child's future outlook These changes induced a renewed interest in spoken language skills and educational achievement and often led parents to investigate the possibility of educational mainstreaming As the child matured, parents aimed for explicit exposure to hearing society They seemed to do so to safeguard their child's future window of opportunity Parents seemed to assume that a deaf child *must* come to terms with his or her disability Parents felt that a fenced-off deaf school setting keeps stigma away from a deaf child yet also felt that ultimately encounter with stigma is inescapable It seems that advocates of Deaf culture prefer to prevent this encounter and thereby launch the idea of a secluded world in which the deaf can "feel good" (Sansone 1992, van Langen 1996) Referring to Nozick, Reinders warns (Nozick 1986)

> The doctrine that experience is all that counts for a good life - the doctrine of hedonism - fails to acknowledge that a life that feels good "from the inside" could depend entirely upon self-deception (Reinders 2000, 168)

Early, yet not too early, contact with societies prejudices was felt necessary to reach a *balanced* sense of self Exposure to hearing society was postulated to eventually decrease the sense of stigma Exposure to society was also felt to be important to become acquainted with the rules of the hearing world If fenced-off too long, as has been the practice in the past, a deaf individual will fail to master these rules, which in turn will be a major obstacle in social functioning To facilitate contact with hearing society parents actively stimulated their child to participate in sports Mainstreaming was also appreciated as an excellent way to achieve social familiarity Avoiding exposure for too long casu quo upholding a protective environment for too long, instates an inflated sense of self-esteem a sense of self that is incongruent with the child's abilities beyond the protective environment Indeed Myklebust has described that adolescents who attended a boarding school for the deaf had such an unrealistic sense of self (Myklebust 1960) Since exposure must occur at some point, parents feared that the disillusionment that this confrontation will instill may promote a rather bitter retreat Parents aimed to prepare their child academically for self-reliance The limited challenge offered by deaf schools was felt to undermine opportunities Spoken language skills rose to the forefront Spoken language was considered important for several reasons, most all of which were located in the future Mastery of some spoken language was believed to increase independent

mobility in hearing society. Spoken language was seen as a prerequisite to open social avenues in the hearing world. Spoken language was also valued since parents perceived of it as a vehicle to obtain an education beyond the program offered by deaf schools. Finally spoken language was felt to increase a child's career abilities. Hearing society was valued higher than Deaf culture in general terms of the most favorable socio-cultural environment. Several reasons explain this. Deaf culture was found to be a limited world in quantitative terms. Moreover, it was not perceived of as a "positive" or "vibrant" culture, but rather as fenced-off and ideological in its views, therefore potentially injuring individuality. Deaf schools were perceived of as the cradle of an exclusionary Deaf culture existence by virtue of their low standards and socializing potential.

> How can anyone possibly succeed...considering the curriculum and teaching methods level in the average deaf residential school? The system is designed to work against them and keeps them out of general North American society. (Tommie Wells, Deaf-L 1997)

Hiddinga, a representative of the Dutch Federation of Parents of Deaf Children (FODOK) underscores the lack of educational quality at some deaf schools (Hiddinga 1998). Hoogeveen found that 98.5% of respondents held the opinion that deaf children should be challenged to their potential (Hoogeveen 1998). Finally Deaf culture was seen as an *exit option*, an option born from the belief that deaf children can do nothing but fail in hearing society. Parents feared that prolonged deaf school exposure, most evidently in the form of deaf residential high school, would automatically result in an exclusive Deaf culture existence, which has also been claimed by Bertling (Bertling 1994). Parents find the prospectiveness of Deaf culture less than ideal, because of the limited range in opportunities that it provides in, its negative attitude towards mainstream society - which includes parents - and the limited freedom it allows for individualism. The latter threat, the threat that an emancipation politics may yield authoritative scripts of what it entails to be a member of the group, has also been expressed by Appiah (Appiah 1994). This critique becomes of the utmost importance in the scenario of "negative identities", identities that design their being around scripts that contrast clearly with the ideal of social participation on the long run, as we will discuss in chapter seven. Even some deaf adults resent the impact of these scripts in Deaf culture (van Noort 1999). Indeed Bolt states that Deaf culture may at times have a "suffocating" effect on its members (Bolt 1998). Provocative deaf author Bertling also has voiced similar experiences:

> Group loyalties have made the deaf community into a rigid conformist society. Thus, anyone trying to "rock the boat", or attempt real achievements threatens the other. I cannot emphasize enough how widespread and infectious this is. Very little true progressive achievements can be made in the deaf community because of the excessive amount of time needed to overcome conformity. (Bertling 1994, 93)

Moreover, parents appear to sense that the formation of an essentialist and tightly scripted Deaf identity robs the deaf of their humanity (Silvers 1998). The prospective of a Deaf culture future troubles parents. Parents seem to sense that prolonged exposure to

Sign language and Deaf culture may invoke an irreversible process. Taken into account the very young age of exposure as well as the "total institution" characteristics of deaf schools, this assumption seems realistic indeed. Laundy and Allard for example have proposed the following tabular model with regard to language minorities in general (Laundy 1998).

Table 4: Laundy & Allard's model

	Positive attitude towards dominant culture	Negative attitude towards dominant culture
Positive attitude towards minority culture	Integration	Separation
Negative attitude towards minority culture	Assimilation	Deculturalization

From this figure is may therefore be suggested that if indeed Deaf adults cultivate a negative attitude towards dominant culture while the attitude towards Deaf culture is positive, this may result in separatist inclinations. Indeed it seems that the "ethno-linguistic vitality" of Deaf culture is relatively high, casu quo the tendency of the deaf to act as a group may be high (Russel 1998). Harris has recently suggested that the impact of the family climate on the development of children is less than commonly assumed (Harris 1998). Instead she argues that the peer group is of much greater significance. In the case of the deaf, a choice for deaf school implies that the child is exposed to deaf peers who may hold a negative attitude to mainstream society. From this perspective parental concern over the influence of this climate on the outcome of their child may not be without reason.

Deaf culture was not seen as something one should *a priori* aim for: while it was seen as a valuable safe haven for some, it was also depicted as a dependent social environment that emphasized stigma (Appiah 1996; Van Noort 1999). Indeed, in our fast changing world flexible and broadly orientated identities appear to have an edge (Bauman 1998; Bell 1998). Parents sensed that a child that retreated into Deaf culture would be vulnerable in adult life. To attain self-reliance parents sensed that specific skills were essential. Spoken language skills, a good educational level and familiarity with hearing society were the most prominent skills in this context. The changing perspective that we described in this section was dependent on the age of the child yet independent on case-control status or region of residence, casu quo school of attendance. Regarding the role of age, we refer to what we suggested in the introduction of this chapter. As we have shown, the new perspective that parents of older children develop is very much dependent on the child him or herself: parents gauge the concerns over emotional injury directly from their child.

Ultimately it seemed that parents did not want to enforce normal society on their child, yet did see it as their duty to at least provide the possibility to choose. Parents upheld their child's right to choose eventually yet felt that to be able to choose realistically, one must attain the values that we discussed above. If no speech develops, if social skills are rather rudimentary, and if educational achievement is deficient the sense of "choice" is symbolic rather than realistic. A deaf child that does not reach beyond grade school achievement, does not speak, has no knowledge of hearing society and never confronted societies views on deafness is likely to "exit" in Deaf culture. Even though parents aimed for real-world opportunities for their child, they never forgot that their child was *not* a regular child. There were two distinct expressions of this. Firstly, parents have rather modest societal expectations of their children. Most of them do not expect their child to become this or that, but rather hope that they will do something that will allow self-reliance to be instated. Secondly, parents fully acknowledge the chance of failure.

Parents seem to realize that DC-ID ideology conceals a one-sided care ideology that excludes the normal world categorically from deaf children. While Lane speaks about the "infirmity model" which equates the medical model of perceiving of deafness as a disease that needs to be cured, it may be more accurate to use "infirmary model" instead. Both infirmity or cure (medicine) and infirmary or care (nursery) are sides of the same coin, namely of a perspective that manifestly renders deafness as a condition that legitimizes treatment based on rules and values outside the normal order. Parents also realize the unfitness of an encompassing care-ideology such as encountered in literature on mental retardation. Much like parents movements in this sector, parents of deaf children renounce how the normal world is withheld from their children categorically. Through experience parents come to believe that their child is much more normal than claimed by deaf ecology and hence that much more can be achieved.

All in all we found that all of our respondents spoke a similar language when contemplating the best-interest of their child. Hence we did not find convincing evidence of "moral pluralism" as a confounder of the actual decisions parents made: we did not find categorical moral differences in our population (Engelhardt 1996). Parents seemed to hold the same values and similar concerns yet decided differently mostly based on local differences. Emotional well-being for example, was an important value to all parents, yet some allowed it to prevail more so than others. This may be explained by local parental preferences, yet local child factors may also be an issue. The same was true for spoken language skills, which most parents eventually valued highly. One factor that may explain why some parents persist in Sign language while others seek spoken language stimulation is their appraisal of the chance that a change in strategy will yield success. It seemed that at least some of the former parents felt that changing the course after having invested in Sign language for many years would not be so productive to legitimate its liabilities. Parents hence organized their rather similar value set based on local circumstances. The relation between parents and deaf schools on the other hand did

appear as one in which different conceptions of the good led "one group…to impose its conceptions on another" (Murray 1997).

Chapter 6 – The Cochlear Implant

INTRODUCTION

So far we have focused in detail on parents narratives without explicitly considering cochlear implantation The issues raised in the previous chapters form the backbone of the cochlear implant decision however By describing the general climate from diagnosis to the time when a deaf child reaches childhood we have covered the period during which parents are confronted with the *possibility* of cochlear implantation While cochlear implants may open a unique experiential register, it is likely that the way implants are experienced must largely originate from the general context described previously

However one puts it, cochlear implants *are* related to hearing and perhaps even speech In particular during the earliest stages of deafness parents grieve over their child's inability to hear If cochlear implants are introduced in this stage, the response may be related to the desire to call an end to "silence", to open up the world of sound to the hearing child cochlear implants could cater to parents silent wish for hearing Somewhat later, parents become convinced of the need for Sign language As such the liabilities of speech that were also raised in the early stages of deafness and on which we elaborated extensively in chapter three, are likely to resurface in this context In chapters three and four we illustrated how parents found a way to deal with deafness rather soon While the route of Sign language was embraced, the motives for this were mostly pragmatic rather than foundational Even though parents were called upon to "accept" deafness, most of them did not in the way suggested by DC-ID Most parents regretted deafness and upheld the idea that resolution of the handicap was desirable, if reasonably possible The aim towards Sign language was therefore mostly founded on the belief that spoken language was not feasible in this phase, at least not at a reasonable price To avoid enduring grief that this conviction could induce, parents made a clear distinction between disability and the affective child The end result was that most parents found peace with their child's situation, an attitude that was enforced by the fact that the child was generally doing well

In chapter five we outlined how most parents came to perceive of their child differently as he or she reached childhood In very general terms, parents became convinced that their child had considerably more capacities than allocated to him or her by deaf ecology Parents also felt that their child was resilient enough to deal with challenges that surpassed those offered by the deaf school environment The child him or herself, who came to function as a real life empirical body, supported parents in this conviction Experience with other deaf children was also a strong support Finally parents became aware of the ideological basis of DC-ID, which liberated them to think beyond the paradigm of deaf ecology As a result, many parents became critical of deaf school and demanded a more challenging approach, both in educational and spoken language terms Parents believed that achievement in these domains was crucial to facilitate independence and an open future at an adult age In particular the signing schools did not

fancy the new demands by parents. By appealing to "good parenthood" deaf schools countered parents in their quest. Conflict was often the result, something that parents wanted to prevent. Clearly, cochlear implants are at least theoretically "fit" for this new parental discourse. Yet implants are also a suitable target of the counter-narrative by deaf schools. As such cochlear implantation is likely to be drawn into the center of the disagreement in a later stage.

In this chapter we will explore our empirical material specifically aimed at cochlear implants. From the above it appears rather crucial to determine *when* parents first heard about implants. Also of importance is the *content* of the initial information and how parents interpreted this information. It is important to know who first told them about the procedure. Yet, the "formal" information provided by implant teams is also of importance. It may also be of importance to focus on possible unique experiential registers. Since implants require surgery, the connotation to "inadequacy" and "non-acceptance" for example, may become even stronger than we have encountered so far. The next stage is to describe specific experiences provoked by the knowledge of implants and to analyze to which of the previously described experiential registers it is possibly related. Did implants function as a "support" to early grievance, to a non-accepting attitude, to the silent hope of hearing, to the new value of independence, to parent empowerment in their struggle with deaf ecology? What did parents hope or expect when considering cochlear implantation? Given the influence of deaf ecology, it is also required to describe how deaf ecology interpreted implants and how *they* represented them in their relation with parents. Finally, we need to describe how parents dealt with this representation.

Next, we need to know how parents evaluated their expectations a posteriori. Dissatisfaction may reveal that expectations did not materialize. It may also however reveal that parents actually expected more than they disclosed. Finally it may reveal that expectations are a "moving target", that parents expect different things at different times, dependent on context (Hoff-Ginsberg 1995). The parent of an implanted child who has attained spoken language may say that *this* is what one expected and may consequentially also aim for "independence" strongly, while the parent of a child who failed in this respect may provide a different discourse. The fact that we have included parents of recently implanted children as well as parents with considerably more experience is essential in analyzing such a moving aspect in a retrospective setting.

WHEN DID PARENTS FIRST HEAR ABOUT COCHLEAR IMPLANTATION?

Introduction

In the previous chapters, we illustrated both the "developmental nature" of parents' views on deafness as well as the crucial role of experts In the early days after the diagnosis, parents were generally distressed, felt powerless and were looking for a "cure" for the misfortune that struck them After some time distress weakened, mostly as the result of a gain in knowledge as well as hands-on experience with the maturing child Sign language facilitated language development and established a parent-child relationship while parents also experienced that their child was doing relatively well in psycho-emotional terms With time many parents were also socialized in deaf ecology, which had considerable influence on how parents thought about deafness Deaf ecology generally had a rather strong view on the state of deafness, the "ideal world" for deaf children and their future perspectives From the above it seems fair to conclude that it is of importance to be informed on both when and through which channel parents first became aware of the availability of cochlear implantation

Hearing about the implant

Parents came to know about the implant through a variety of channels and time frames A minority of parents (n = 3) was informed by (para-) medical personnel or by audiological center staff in the earliest days of their child's deafness (C3b)

M At the university hospital they told us that something new was discovered They were very careful in their words yet we grabbed it with both hands
I While she was still in the hospital?
M Right after her hospital stay within a month or two [ ] It was a social worker I think someone whom I was speaking with about these things (C12ab)

M It was a few months after [the diagnosis]
I Where did you hear of it?
M At the audiological center in Nijmegen (C2b)

Most parents however, learned about the implant in a later stage

M At a certain moment we started reading about it about CI
I You encountered that information instantly?
M No not instantly of course In due time we heard about it (C14b)

Exposure to the implant occurred in deaf ecology mostly. School and diagnostic center personnel that stood positive towards cochlear implantation often provided the initial information (C3b; C4ab; C9a).

> *F: We found out about the implant some years after she became deaf, through her school [for the hard of hearing -- ccw]. (C4ab)*

> *I. When did you first hear about CI?*
> *F: At her previous school.*
> *M: At the school for the hard of hearing that she was attending, they brought it to our attention. (C15)*

> *M: We attended a communication weekend for parents and children At one moment she [NSDSK executive-ccw] sat beside us.*
> *F: We were just having a nice evening with some snacks and drinks. So she came to us and said: "you are interested in cochlear implantation aren't you?" (C14b)*

A third route through which parents became acquainted with cochlear implantation was direct experience with classmates or schoolmates who were implanted (C6). As one would expect this was mostly true for parents of children who were implanted fairly recently.

> *M: Well, I think that when she [implanted daughter] entered that class, other parents could see that it actually works and that it may be something for their own child. So they applied for cochlear implantation as well. There are five children with an implant in her class. And parents of some other children also want to talk with us about it. [...] It is sort of a snowball effect. Like, "maybe that is something for our child too" (C13)*

> *I: When did you first hear about the implant?*
> *M: At school. At the institute. One of his classmates was implanted a year earlier (C16b)*

> *M: He did not attend school yet [when parents first heard of CI-ccw]. There was this girl that was operated. She attended a school nearby and I heard that she was doing really well.[...] I met her mother and she told us about it, that things were going really well. (C8b)*

Finally, some parents first heard of the implant through the popular media. This was true for 3 parents, all of whom (C1a, C7a, C12ab) had their child implanted at least five years prior to the interview. During the introduction phase of cochlear implants in The Netherlands in the late 1980s and early 1990s, several newspapers, magazines and TV programs paid attention to the technology. Apparently, implant teams actively sought media coverage.

M: We heard about it at a parent meeting in 1988. One of the parents had read about a "plastic ear" in the newspaper. [...] In a British newspaper.[...] So we called them [implant center] and were invited for a meeting. (C1a)

Specific issues, cases and controls

Based on our material it seems that some schools for the hard of hearing, IvD, Nijmegen University Audiological Center (AZN) and the Amsterdam-based NSDSK actively engaged parents into the dialogue about CI. One sign-oriented school also appeared to provide information on cochlear implantation to parents. The active involvement of IvD and Nijmegen University Audiological Center is not much of a surprise since these two institutions constitute the largest pediatric implant center in the Netherlands. Most schools for the hard of hearing involved in this study were in the vicinity of Nijmegen University and IvD. It could be suggested that because of this proximity and the professional cooperation that results from it, these latter institutes were more knowledgeable about CI. The second sign-oriented institute in our inventory however apparently did not provide much information to parents. Only one parent associated with this latter school attested that she first heard from cochlear implantation through a school social worker (C7a). This parent added that:

F: That was not the schools policy [to provide information on CI-ccw].
M: No, it was sort of secretive. (C7a)

Awareness of cochlear implantation did not differ in our control group: all of our controls were aware of cochlear implantation, two of them early on.

F: We knew about it [CI] from the start A lot of information came our way. We were given booklets by the audiological center: One hundred questions about deafness, things about their development. One of the things that these booklets elaborated on quite extensively were the newest developments with cochlear implants (CO4b)

F: They [audiological center] told us: "who knows how the technology will develop". They spoke about cochlear implants, a new prosthesis technique that was under development. It was too early now, but perhaps something for the future. (CO5b)

Conclusions

Parents first heard about cochlear implantation though a variety of channels and time frames. Several parents were informed about the technique early on at the diagnosing center. Others were confronted with schoolmates who had been implanted: this was particularly true for parents of more recently implanted children. Many parents were updated by deaf school personnel. In particular parents of the earliest implanted children

read about cochlear implants in popular media or had seen coverage on television. All controls were equally aware of the availability of cochlear implantation.

WHAT WERE PARENTS TOLD?

Introduction

Deaf adults and others critics of cochlear implantation have argued that the available information on cochlear implantation has been skewed heavily towards the positive. This is considered an unwelcome situation since it is believed to cater to parents' desperation, in particular in the period directly after the diagnosis. One of the key liabilities that has been stressed by critics is that the procedure does not yield success in all cases and that it has proven very difficult to predict who will and who will not benefit. This implies that cochlear implantation is an uncertain avenue indeed. Meanwhile there is an alternative available in the form of Sign language submersion. While this alternative may not yield significant spoken language skills, it is at least in concordance with the retrospectively formulated desires of Deaf adults. Moreover, at least theoretically, it provides a basis for deaf children to advance in general language terms while steering clear of stigmatization and "injured" identities. Unrealistic information vis-à-vis cochlear implantation may inhibit parents to appreciate the alternative of Deaf culture fairly. Parents risk blindly choosing for an implant based on ultimately unattainable grounds, thereby missing an opportunity to consider Sign submersion as a realistic option. As such parents may more or less unknowingly implement a future for their child that is based on misinformation, while shutting the door for Deaf culture when their striving turns out a failure. It is rather self-evident that such a situation is unwelcome. Providing factually correct and balanced information is the responsibility of implant teams first and foremost. In this section we will analyze our material on the content of this information. While the information provided by implant teams is crucial, parents also received information through other channels as we discussed in the previous section. The media for example, was an important source of information for the most experienced parents in our sample, a source of information we hence need to describe and analyze.

What were parents told by the implant team?

As we discussed in the previous section, a few parents heard about cochlear implantation in a very early stage, when the procedure was not even available for children. The earliest media coverage on the procedure pertained to implantation of adults exclusively. When parents nonetheless inquired about the feasibility of implants for their deaf youngster, they were told that it was as yet unavailable for children.

> *M: It was in 1988 They [audiological center] distanced themselves from it. [. .] In The Netherlands they had just started with adults, so they distanced themselves from it. (C1a)*

Yet, by the end of the 1980s cochlear implantation did become available for children Through several channels parents started to find their way to the AZN-IvD implant team. The homogeneity in parents' narratives suggests that implant teams thoroughly prepared their pediatric program. The single most striking element in parents' narratives was the "reservation" of the information provided. From most interviews it appeared that implant teams were highly prudent about the potential benefits of cochlear implantation. Parents reported that the information was rather factual, carefully evading far-reaching hopes of speech and normalcy that parents of deaf children may have

M The information brochure was not optimistic it just stated the possibilities (C10ab)

Parents were told that the implant would likely establish *some* hearing, yet emphasized that any expectations beyond this were uncalled for.

I What was the main message conveyed to you?
M That she would be able to hear something again That she would be released from that soundless vacuum that was the message How well and how much hearing? I do not recall, they were very vague about that - righteously so (C12ab)

On the other hand, the modest expectations were countered by the severe status of hearing loss. Implanted children are *totally* deaf, which appeared to instigate a discourse that legitimated ány attempt to improve hearing Many parents said that one reason to choose for an implant was to call an end to the total silence in which their child was submerged (C3b). Consequently some reasoned that *any* gain in hearing legitimated the procedure.

M We started with cochlear implantation with the idea that ány gain that it would result in is a bonus (C7a)

F I also think that [we did it to] break through the absolute silence However little look someone with some hearing remains at least hears something But if you hear nothing at all, that is of course (C9a)

F It is also something emotional as parents, like "if only he would know what sound is " (C14b)

I What was the decisive motive?
F That she would perhaps hear a little
M Yes
F Nothing at all is so nothing you know (C2b)

F We felt that we hád to do this for her and for the rest we would just have to wait and see how it works out Everything is better than what she has now (C4ab)

M: They [implant team] told us that he would never hear like a normal person and all that. We were given a lot of information and read through it Still I felt that even if he would gain a tiny bit, it would be better than hearing nothing at all. (C8b)

Still others were able to relativize this issue. Some parents appeared to realize that the issue of "silence" in itself might not be sufficient to legitimize an expensive and invasive procedure such as cochlear implantation.

M: I know what others will think. Like: must that cost so much money? [...] But who is to say? (C9a)

If a link to speech was made, this was mostly restricted to anticipated improvements of lip-reading skills as well as voice quality.

M: They told us that we should not expect too much, that it would be a support but would not return her hearing. That it was a support for lip reading [...] that she would have access to some sounds, but different from a hearing person. That she had to get to know sound from scratch. That we should not expect that she would be able to hear without lip-reading. (C1a)

M: They told us that we could expect that he would hear sounds, but not how much. It was also shown they said that speech generally improved. (C3b)

Given the experimental nature of cochlear implantation and the variable results, at least the parents of the earliest implanted cohort were notified that no guarantees could be given.

M: They told us immediately that it could turn out to be a failure as well. (C2b)

In addition, parents were told that "success" could not be achieved by implantation alone: a long and laborious revalidation process was essential.

M: We were given several brochures and were given the opportunity to actually see the children. All along they [implant team] were saying that they could not give any guarantees, that the selection process was tough, that the revalidation required a lot of energy. Yes, the negative side was stressed very well. (C12ab)

It hence appeared that implant teams made an explicit effort to temper expectations, something that has also been reported by Blume (Blume & Yardley, manuscript).

M: We were tempered in our expectations. They were very conservative with their information, like "you should not expect too much from it". (C10ab)

Implant teams seemed to stress the strict selection process, something that was not valued by all parents This was particularly true for the eldest children in our study who were implanted as part of the initial Technology Assessment trial

> *F There were limited means and people would have to compete for it (CO5b)*

> *F We knew nothing about cochlear implantation and were approached by the school [for the hard of hearing] They explained to us that there was a project with a government grant for CI, and they were looking for a limited number of children Our daughter fitted the description (C4ab)*

The sense of competition may be argued to rhetorically enlarge the sense of gratefulness if one's child *was* selected eventually.

> *F By the grace of God he was allowed to participate [in the initial trial], there were very few kids implanted back then you know (C3b)*

What were parents told by the popular media?

The popular media were less prudent in their coverage of cochlear implants implants were represented rather positively, parents felt The earliest media attention focused on implanted adults mostly.

> *F We had heard about it through the newspaper On Bets van Bekkum [implanted deaf adult], an entire article (C9a)*

Later on, the media did target pediatric cochlear implantation specifically Contrary to the information supplied by implant teams themselves, speech was sometimes an explicit part of the conveyed message (C6; C9a)

> *F There was a deaf boy on TV*
> *I In the early period?*
> *F Yes, and they were filming him, recognizing speech without visual clews He could repeat word for word what was said to him from a distance [ ] It was an exceptionally successful case it turned out later (C7a)*

Sometimes it was suggested that some implanted children would no longer be deaf after implantation

> *F There was this article in a newspaper, and it said that 15-20% of deaf people could benefit from it and no longer needed to go through life being deaf A deadly issue to raise vis-à-vis the Deaf community (C5a)*

Cochlear implants were presented as a "miracle cure", some parents felt.

> *M It [media coverage] enforced me in my ideas German television showed the operation and all that they could achieve Especially TV and newspapers presented it as a miracle cure (C12ab)*

> *M Making things more beautiful than they are, that is typical for newspapers They make it beautiful or terrible neutral is no news (C12ab)*

Specific issues, cases and controls

The story told by our respondents was highly homogeneous: no significant inter-individual differences were observed with the exception of one parent. Being the parent of a child with severe co-morbidity appeared to trigger a rather unique discourse by the implant team.

> *M He [implant team surgeon] knew our son and that was important He knows about him and felt that he "deserved" the implant*
> *I Why?*
> *M Because he [son] had gone through so many problems He [implant surgeon] felt that it was important for our son that he could hear something, that his mother could speak with him [...]*
> *I You say that your impression was positive?*
> *M· Very positive. .like I could speak with him and the cardiologist could speak with him and explain why he was disabled so much (C16b)*

Having so many disabilities seemed to prompt a sense of injustice, which consequently may lead to different inclusion standards, though we do not know this for sure as the medical details of C16b are unknown to us.

Conclusions

The information parents received from implant teams was highly homogenous. In general the tone of the information was rather prudent. Parents were told that while the implant could reinstate some hearing, it would certainly not make their child a "hearing child". Lip-reading skills were likely to improve as well as the quality of speech. Implant teams emphasized the uncertainty of the results and underscored that "no guarantees" could be provided. In addition they informed parents about the importance of the lengthy and laborious revalidation process. The selection procedure was depicted as "tough", which may instill a sense of competition and heighten the feeling of gratefulness once selected.

The media represented cochlear implantation much more positively, though this was particularly true for adult implantation. In table 5 we have listed some of the publications that we retrieved through the IvD archive.

Table 5: Publications 1989-1996 in the popular media

Source	Title	Year	Child or adult
Libelle	Fantastic medical news: operation can give deaf people their hearing back	1989	Adult
Brabants Dagblad	Earprosthesis: hearing sounds, not speech	1989	Adult
NRC	Deaf woman astonished to hear sounds again after implantation	1989	Adult
De Stad Amersfoort	Bets van Bekkum hears again after 43 years	1989	Adult
Stads Journaal	Bets hears own voice after years of silence	1989	Adult
Margriet	I can hear again!	1990	Child and adult
Telegraaf	Learning to hear with a cochlear prosthesis	1994	Adult
Het Beste	Professor Clark and the bionic ear	1996	Child
Libelle	News about deafness	unknown	Child

The titles summarized above, illustrate that many of the early publications pertaining to adults at least suggested rather positive results ("fantastic news", "deaf woman astonished"). Moreover, these titles are rather melodramatic as they appeal to regaining a lost function after many years as well as the assumed agony of silence. Titles pertaining to pediatric cochlear implantation are more reserved. A noteworthy finding is that many articles spoke of a cochlear "prosthesis" rather than an implant.

Below we have reprinted parts of the content of the publications related to children.

> Janny, Birgitta and Miranda were deaf. Environmental sounds, music, the telephone ring, the voices of people around them...everything went passed them. At least until recently: a spectacular, new operation has called an end to the silence. Read their remarkable stories. [...] With a cochlear prosthesis it is usually not possible to capture speech - though this differs individually - but it is of support for lip-reding. One can hear if people are speaking normally or with a loud tone of voice. Excited or calmly. In company of other people, one can decipher who is speaking which facilitates the speed at which one can turn to that person to establish lip-reading. Also there is better control of one's own voice. [...] Brokx: "People who have been deaf from birth and first perceive 'hearing sensations' initially do not know to place this. They feel with their legs, arms, and elbows and only after time they realize that what they perceive is sound. That is experienced very positively". [...] Birgitta

was struck by meningitis when 2-years old which caused her to become completely deaf. [...] slowly but surely her parents could see their daughter change. Initially they had not expected that she would learn to speak but notice that she is with the aid of the implant. Mother: "If she plays and the device is on, she makes sound. Babbling. Just like when she was a toddler. If you turn the device off, she becomes completely silent". Father: "Her vocabulary is also expanding. In January she used about ten words. About one hundred were added". [...] "What we did", her mother says, "we consider an investment for the future. Maybe, just maybe, she will be able to attend a mainstream local school in the future". Father: "But that is not certain. There is so little experience in this field". (Margriet 1990-translation ccw)

A routine check-up yields that Teigan van Roosmalen, a ten-month-old Australian baby, has a hearing disability. [...] After a long day of exams, her parents are told the terrible news. "Teigan is completely deaf", the specialist said. "She hears nothing at all". The only hope he feels is an implant to the cochlea, a bionic ear that will be implanted in the skull of the baby. [...] In 1984 over 50 people were implanted with a bionic ear with variable results. For people who lost their hearing at a later age, the sound was sometimes described as natural while others found it metal-like, like a computer voice. All patients required speech therapy. But without exception they smiled when they first heard sound and most of them cried. "It was beyond words so great when I could hear my daughter's voices again and hear the birds sing" says the 57 year old journalist Peter Steward from Victoria...[...] In the center for hearing implants the moment of truth has arrived for Michael and Derrian van Roosmalen and their daughter. "We are ready" says the audiologist. The transmitter that sends sounds to Teigan's implant is switched on. The audiologist pushes a button, which results in an electronic sound signal. Teigan turns around immediately, her eyes wide open. Her face radiates as she points to her ear. It works! Blissfully happy Derrian embraces her daughter and falls into tears. Clarks device has triumphed again. (Het Beste 1996-translation ccw)

Reading through these excerpts, several things of interest are revealed.

- Cochlear implants allows one to decipher environmental sounds
- Speech is not the usual results of implants, but may arise nonetheless
- Cochlear implants assist in lip-reading
- Cochlear implants provide a feed-back loop, which benefits speech quality
- Cochlear implants are depicted as an investment in the future
- Results for pre-lingually deaf children are not the same as for post-lingual deaf adults
- The issue of pre-lingual deafness if mixed-up with post-lingual deafness

One issue needs to be highlighted here since it seem rather important to us: it is evident that in many of the early publications, testimonies by post-lingual implantees are mixed with the issue of pre-lingually deaf children. This rather confusing and misleading situation is encountered in the official AZN/IvD cochlear implant brochure as well. We consider this of importance because it could imply that parents retain the positive testimony by satisfied implanted adults.

DEAF ECOLOGY AND COCHLEAR IMPLANTS

Introduction

As we illustrated in chapter 5, deaf ecology is an important sounding board for many parents, those residing around the Guyot Institute and the Amman school in particular. While the "formal" information provided by implant teams is relevant without question, it occurs rather late in the process and is also limited in terms of exposure. It seems reasonable to assume that by the time that parents actually visit an implant team, they have already gone through a process of deliberation. Given the role of deaf ecology, in terms of their view on issues such as spoken language and mainstreaming, it appears likely that this environment will also play a significant role in the case of cochlear implantation. Be it before parents physically visit an implant center or afterwards, parents are likely to encounter a specific discourse on cochlear implantation, which may add to their end-view on the procedure. Given the degree to which parents are intertwined with deaf ecology, this discourse is likely to have at least the impact that implant team information has. In this section we will describe parents' experience with deaf ecology in terms of cochlear implantation.

The role of deaf ecology

The role of deaf ecology was by all means significant. In general deaf ecology was critical about cochlear implantation. Deaf adults in particular, often fiercely rejected implants. Parents heard about the opinion of Deaf adults through a variety of channels. Deaf adults were sometimes a part of parents' deaf ecology.

> *M: We were attending parent's day recently and this deaf couple was also attending. The father suddenly charged at us, really*
> *F. Yes, charged at us, like "why are you giving your child an implant, what purpose does it serve!" (C14b)*

One of the most important channels through which parents learned about how Deaf adults viewed cochlear implants was through meetings held especially on the topic. One such information-day was organized in Nunspeet on October 26-27 1995. Quite a few parents made reference to this specific meeting (van Langen 1996).

> *M: I went to that conference in Nunspeet. They [Deaf adults] really charged at implants during that meeting (C10ab)*

> *M: Deaf representatives were charging at implants [...] I felt in the line of fire...(C13)*
> *F: We attended this meeting...and representatives of the Deaf community were also present. They were against everything really (C2b)*

Cochlear implants were "ridiculed" at this meeting one parent felt, even though one attending journalist interpreted this differently (Van Langen 1996).

> *M: When we attended that conference I instantly noticed what was the matter. The air was very negative. They had invited a deaf actor; he was making mockery of CI. (C13)*

Yet the interference of Deaf adults and other critics was not limited to opinion encountered in deaf ecology or at specific meetings. Some parents received uninvited negative mail.

> *M: All those things that we were sent by mail since we started with CI. Negative, a lot of negativity from the Deaf world. That really makes me sick. (C7a)*

Deaf ecology charged at cochlear implants with a variety of arguments. These arguments were generally congruous with the arguments against oral education and mainstreaming that we described in the previous chapters. Similarly to what we described in chapter five, the arguments can be arranged as 1) child-centered, "empirical" or at the level of construct validity and 2) parent-centered, "moral" or at the level of content validity.

Debate on "construct validity" does not question the concept of "benefit" in itself as defined by implant teams. Rather it questions if these benefits have adequately been deducted from the available empirical material. As many critics have, Deaf adults and others in deaf ecology questioned if the promises of cochlear implantation can be met (Kamerling 1994). Parents were hence called upon to refrain from implantation, because it was considered an unproven technology that stood a good chance to fail.

> *M: There has not been enough research. It is dangerous because it was still experimental medicine, they argued. (C12ab)*

Parents were warned that, since implantation was unlikely to make their child "hearing" and since the Deaf community did not accept it, their child would be at risk of lacking the opportunity for social-identification.

> *F: Like: "Your kid won't belong anywhere, not with the Deaf and not with the hearing. How can you do that to your child? In Gods name, forget about cochlear implantation and teach your child to sign. Make him a part of the Deaf world." (C4ab)*

Given the assumed low chance for success, the risks of the operation itself were also highlighted (Kamerling 1994).

> *M: Were we to expose our child to such a large operation for thát? [...] They argued that it was a heavy operation and things could go wrong. C2b)*

Sometimes fallacious arguments, which may be attributed to misinformation, were also raised.

> *M: They [deaf parents of deaf child] said that our son would never be able to swim.... (C14b)*

Some parents were told that their child was "unfit" for cochlear implantation.

> *M: We talked about it with our social worker. She told us that it could not be done in children who were born deaf. (C14b)*

Content validity was also drawn into question. Perhaps in a response to the positive testimony by post-lingual implanted adults in the popular media, Deaf adults argued that *they* did nót yearn for sound (Kamerling 1994).

> *F: He [Deaf adult] said: "Look at me, I never miss it, music and what ever else. I never yearn for it". (C14b)*

Yet parents countered this argument by pointing out that some Deaf adults do actually use hearing aids. In doing so, the choice for an implant was more or less synchronized with the choice for a hearing aid.

> *M: I told him, like: "You do wear hearing aids don't you? Why do you wear them? Right, to make use of the hearing remains that you have, to make things easier." So I said: "But he [deaf son] has no use of hearing aids. No use at all." (C14b)*

Similarly to what we discussed in chapter five, the "good parent" argument also surfaced in this context. As we argued, this argument has several distinct ingredients. One ingredient is related to parents' coping strategy. A second part is moral-affective in content: a parent that chooses to recover hearing apparently does not find his or her child "good enough" (unconditional love). A third ingredient we linked to tolerance or "good citizenship": since deafness is an identity trait, it is simply wrong to try to undo it.

Indeed, parents who chose for an implant were depicted as parents who did not "accept" deafness. Any attempt to recover hearing was thus depicted as a sign of non-acceptance.

> *M: They were like, "what are you doing to your child?" [...] Like, "you must accept that your child is deaf". (C12ab)*

Since deafness was depicted as an identity trait, the choice for cochlear implantation was represented as morally questionable indeed.

> *M: They were opposed to CI, because you were born deaf and it should remain that way. One should not try to change it. (C2b)*

F: We were called "child molesters" etc. How in Gods name did we come to the idea to let our child be implanted, undergo that operation You had to accept that your child was deaf and that was it They belonged in the Deaf world (C7a)

Deaf adults feared that once a child was implanted, Sign language would be tapered or even eliminated.

M: So they had quite a few preconceptions, like "he is deaf and Sign language is his mother language" So I said: "Do not worry, it will continue to be his mother language". They were afraid that I would take Deaf culture away from him...(C14b)

A fourth factor was rather similar to what we have labeled "dismantlement" of parenthood in chapter five. Deaf adults argued that it was not up to parents to decide on cochlear implantation. The right of hearing parents to make decisions for their deaf infant was sometimes contested (Bertling 1998).

M: They said that child custody should be taken away from us It was a battle. (C12ab)

Yet even though the right of parents to decide was contested, what followed was not so much a battle over custody but rather a defense of the child him or herself as the one who ought to decide.

M: They argued that we were not allowed to decide. We had to wait until he was old enough to decide for himself. We tried to explain that waiting could imply that he was no longer fit for the procedure. Well, that was too bad [they reasoned]. (C12ab)

M: He [Deaf parent of deaf child] said that he [deaf child] should decide for himself, when 18. We responded that such was impossible, because he would be too old. (C14b)

M: There were many [Deaf adults] who were saying: "You should let the child decide". It will be too late then! (C9a)

A fifth ingredient of the critique by deaf ecology was similar to the threat of condemnation that we discussed in chapter five. Parents were sometimes made to fear that their child could come to blame them for having decided positively on cochlear implantation.

I: What were the arguments you formulated against implants after attending that meeting?
M: Well, that something could go wrong of course, that perhaps it would not work That - given that the adult deaf also still talk about it - the children will suffer emotional trauma. Those kinds of things. You think that you maybe hurting your child, that she will suffer from psychological problems later. That we would get a sad child, while she is so happy now..
I: Do you worry that she would blame you sometime?

M: Yes, I think I do .I think it will remain until she is grown up. I feel tense about that at times... (C2b)

The chance of condemnation was sometimes substantiated by rumors of non-use.

M: I have heard about a boy, he is 8 or 9 years old. He told his parents that he did not want the implant any more (C2b)

Deaf school personnel sometimes also expressed their discontent over parents' decision.

M: Their attitude was, like: "well, maybe you are happy with it, but we do not stand behind the decision to give him a CI". (C14b)

M. They [signing deaf school personnel] were just fiercely against our decision to option for CI.
F They were very critical
M: They did not support it at all. (C15)

The educational cooperation with implanted children was not ideal.

F: So we entered a battle. They were like: "Your child is the only one with an implant, this is a deaf school, so it is your problem You may thank God that we allowed her to be implanted". It was almost as if we had to be thankful that they cooperated (C7a)

Indeed some parents underscored that this situation made them fear "expulsion" from an institute on which they were highly dependent.

M: The institute did not exhibit the least interest over how things were progressing [after the child was mainstreamed - ccw], so we did not have the feeling that we would be welcomed wholeheartedly [if we would want her to return to deaf school - ccw]. We left and their attitude was. it was your choice, we respect that but you'll have to live with it. (C9a)

Specific issues, cases and controls

Similarly to what we found in chapter five, most of the negativity surrounding cochlear implants in deaf ecology was experienced by parents whose child attended a signing school for the deaf: of nine parents paraphrased, 7 were related to one of the sign-oriented schools for the deaf around the time when the CI decision had to be made. This finding stresses again that deaf ecology has a rather different structure and impact on parents depending on which school their child attends. Parents attending one of the sign-oriented schools were confronted with fierce critique on implants while those in the southeast were much less. Some parents residing in the southeastern provinces did not appear to have had access to Deaf culture critique (C1a, C2b).

Conclusions

The role of deaf ecology was significant and very similar to the discursive disposition of deaf ecology that we described in the previous chapters Deaf adults were generally fiercely opposed to cochlear implantation, though we warn that most of these chronicles were based on the opinion of a few Deaf adults and therefore may not be representative for Deaf culture as a whole Quite a few parents (4) memorized the 1995 information day on cochlear implants, which was held in Nunspeet, as evidence of the denunciation of cochlear implantation by the adult Deaf population The opposition against implants was both child-centered and empirical as well as parent-centered and moral in character Regarding the first, in particular the efficacy of cochlear implants to actually improve spoken language skills was brought into question Dutch Deaf spokeswoman van de Garde has also claimed that implants will at best benefit a deaf child in the home environment, an improved ability to maintain oneself in the hearing world is refuted (van Langen 1996) Regarding the second the full array of arguments discussed in chapter five was encountered The "good parenthood" argument was encountered both through appeals to "unconditional love" as well as "tolerance" The latter is not a surprise in a 1994 article in the widely read journal for the Deaf "Woord & Gebaar", implantation was depicted as "identity-surgery", comparable to trans-gender surgery (Kamerling 1994) Parents were also made to fear condemnation by their child, once grown up Deaf school personnel were critical of cochlear implantation, and did not hesitate to demonstrate this explicitly Sometimes the dependency of parents was misused as parents feared expulsion There was a distinct difference between parents whose child attended one of the sign-oriented schools for the deaf and those whose child attended a school in the southeastern provinces of the Netherlands parents attending one of the sign-oriented schools for the deaf were confronted with fierce critique on implants while those in the south were much less

We also found that the right of parents to decide for their deaf children was contested, even though no alternative tutor was presented as clearly as in chapter five Expecting young pre-adolescent children to decide in the case of cochlear implantation is a rather questionable demand The ability of children to decide in the case of medical care has been studied extensively Buchanan and Brock have provided a helpful summary in this context (Buchanan 1989) While young children have more cognitive abilities than sometimes attributed to them, to expect them to understand the impact of pending medical decisions is rather unreasonable As Buchanan states "The principal understanding children need for most treatment decisions is not of technical medical data, but the impact that treatment alternatives will have on their lives" (Buchanan 1989)

> An important part of children's and adolescent's interest in self-determination is not their interest qua children in making decisions for themselves, but their interest in developing the capacities to be self-determining adults [ ] Self-determination is principally, or at

> least significantly, to be achieved in the future by children and adolescents rather than exercised while still children and adolescents (Buchanan 1989, 231)

This is especially true for cochlear implantation, since "benefit" is located rather far in the future and is defined in rather abstract terms. In terms of the values held by children, there are some serious limitations that need to be considered when decisions affect the future most explicitly, as is the case in cochlear implantation. Young children's values are known to be instable and children have difficulty in anticipating their future. "An important issue" Buchanan states, "is the extent to which children's values adequately reflect future interests" (Buchanan 1989). The author continues to conclude that "this can lead to two important problems: children may give inadequate weight to the effects of decisions on their future interests, and also fail to anticipate future changes in their values that may be predictable by others" As such placing restrictions on children's autonomy can be an act that very much originates in love and concern.

> An important point should be noted here Restrictions are placed on a child's liberty because without these restrictions, the child might harm himself or not act in his own best interest [ ] A conflict, therefore, exists between a desire to respect the dignity of a child and a desire for the child's protection (Abrams 1979, 160)

In more fundamental developmental terms, such as the locus of control (which is mostly "external" in 6-12 year olds), role-taking skills and the ability to perform inductive and deductive operations (at age 5-7 Piaget defines thinking of children as "magical"), pre-adolescent children often (depending on exact age and individual variation) lack the ability to truly decide by themselves. It seems fair to conclude that, given their age (generally under 5 years old) to expect that implant candidates decide for themselves is a questionable undertaking.

HOW PARENTS INTERPRETED THE INFORMATION

Introduction

However concise information is provided, one can never circumvent the auditor fully In this sense, a message is like any other text a text is written by an author in a specific context and with a specific intent, yet it is also read by a reader with a specific biography and a specific purpose This is perhaps even truer when the text in question is opinionating in nature This is one of the key concerns that complicates the informed-consent issue A patient cannot be perceived as a *tabula rasa* he or she too embodies a unique biography and has a specific purpose for visiting a physician This will deeply impact how information is perceived In the previous two sections we outlined the information parents received from implant centers, through the popular media and through interaction with deaf ecology Given what we have just stated, it cannot be assumed that parents interpret this information on face value Rather it is more likely to find a place in their specific context, a context that we have described in chapters three through five In this section we will look for utterances that are related to how parents interpreted the information on cochlear implantation as supplied by implant teams, the media and deaf ecology

Interpreting information provided by implant teams and the media

Some parents (C10ab) welcomed implant teams reservations, reasoning that conservative information is the *only* truthful information in the case of pediatric cochlear implantation One parent argued that parents of deaf children are naturally inclined towards the positive, which entails a risk to "hear the positive" only so to say The careful and downcast tone by implant teams was perceived as welcome counter-balance

> *M Especially on TV and in the newspapers it was really presented as a miracle cure They never did that at IvD [ ] I think that was good [ ] you have to because parents are inclined towards the positive side So it is good to balance things (C12ab)*

Yet others did not welcome this prudence Some parents appeared to have desired more positive and more "convincing" information Perhaps in a desire to be convinced in light of the pre-existing taunting doubts, one parent commented

> *M At the implant team they were very careful with information I thought every time I visited be more enthusiastic guys! They were so temperate (C15)*

Notwithstanding the emphasis on the negative aspects of CI, many parents were "sold" on the technique rather instantly. Even though many sought out information beyond that provided by the implant team, this did not temper their enthusiasm.

> *M I did not even waver for a second [about the implant] Sure, I gathered information, I spoke with parents of implanted children, and I visited these children as well as implanted adults So it was not a superficial feeling, but still I had a positive feeling from the start and it has only been confirmed (C12ab)*

> *I How did you feel after that meeting [first information meeting on CI]?*
> *M This is it! (C1a)*

> *F We were enthusiastic from the start (C4ab)*

One parent revealed that her enthusiasm might have been due to a lack of knowledge

> *M It was instantly clear for me This was likely the result of the fact that I knew too little about it (C12ab)*

Even though the popular media tended to present the implant as a "miracle cure" (C12ab), parents said not to have been influenced by this very much

> *I What was the message in the media?*
> *M That they would be able to hear bits and pieces, rather different from a hearing person and that lip-reading remained important*
> *I What did you think when you read it?*
> *M It is a good support (C1a)*

The response to deaf ecology

Parents were startled by the fierce rejection of cochlear implants by the Deaf community, a finding that has also been produced by Christiansen (Christiansen, in press).

> *I How did you experience this? [Nunspeet conference]*
> *M It was very difficult I am afraid to admit to Deaf adults that I actually have an implanted child I keep that to myself (C13)*

Generally parents were affected by these charges against cochlear implantation Some parents started to avoid discussion.

> *M We argued about it so often At a certain moment you just cease to talk about it It is just very annoying You have to defend yourself constantly, why you chose for an implant That is really difficult to keep doing since it was a tough decision for us as it was At a certain moment you just have enough of it (C15)*

Some parents were intimidated by these charges, and came to question the legitimacy of their plans or actions.

> *I: How did you experience that [critique]?*
> *M. Well, you feel like you have made the wrong decision. (C14b)*

> *M: It really brings you in doubt. You think: "am I doing the right thing?" I felt it was very difficult They [deaf adult] were really hacking away on it like: "it is wrong what you are contemplating". So I was like: "what am I to do?" (C2b)*

It was postulated that some parents might even withhold cochlear implantation because of this (van Langen 1996).

> *M. One person may dare to choose for an implant while another may not have the guts. There are quite a few people who just do not dare to choose for an implant. (C15)*

As a consequence, some parents were grateful that they had taken the actual decision *before* they were exposed to Deaf culture critique.

> *M. We had the advantage that he was still at home when we actually signed him on for CI We had little contact with others, so that makes things different. Once you get into Deaf culture, you will be affected by their emotions, you will reckon with it (C14b)*

Yet while knowledgeable of the position of Deaf culture, some parents said not to have been affected by it in their decision process.

> *I. Did you know how the Deaf world felt about cochlear implants at that time [when the decision was made]?*
> *M: Yes, but it did not affect us much.*
> *I. Did you incorporate their position in your considerations?*
> *M: No, not at all (C10ab)*

Most parents were critical of the negativity that they encountered in deaf ecology, which appeared to empower them against this critique. Parents perceived of the Deaf community's critique on implants as, in part, a political struggle over public attention and funds. This more or less deferred the issue to a "conflict" between deaf adults and children, as we also described in chapter five. At the time when implants were introduced in the Netherlands, the issue of Sign language recognition was high on the political agenda. The shortage of funding for Sign translators was and is also an issue. Funding for cochlear implants may have been perceived as a threat to these developments for Deaf adults, some parents suggested (Kamerling 1994).

> *M: For the deaf, well they may feel like: maybe we will not get subtitling on TV. Sign language is not arranged properly and maybe all the funds will go to the implant So those frustrations may have played a role (C9a)*

F: I know that Deaf people who reject cochlear implants feel that the money could better be spend on Sign language, to make it available in schools and universities. That cochlear implantation is a waste of money That makes me feel· "You can't do that guys!" (C4ab)

Alternatively parents felt that some Deaf adults may have perceived of implants as a threat to the preservation of Deaf culture (Kamerling 1994). If cochlear implants would succeed to implement spoken language skills in a considerable number of children, the influx of Deaf culture could be reduced.

F: They see implants as a threat to the Deaf minority. Just the idea like: every deaf person must have an implant. So that scarecrow comes to life. Like, we do not have to battle for subtitling anymore, because everyone will have an implant and the problem is solved. So if you implant all deaf children, the signing Deaf population would cease to exist in the end. (C9a)

M: I could sense in their [Deaf adults] revolt that they feared it would limit new membership to the Deaf community. They feared that people with a cochlear implant would do away with Sign language and only aim for a life in the hearing world, thus limiting new members for their minority culture. (C13)

Some parents relativized the critique by arguing that Deaf adults just cannot imagine the benefits of cochlear implantation since they, as opposed to children, have been socialized in a world in which sound does not matter indeed.

F: I just think, "another deaf adult who does not know what it [CI] is". (C2b)

Some parents believed that "envy" played a role in Deaf adults' rejection of cochlear implantation, knowing that the technology passed them by irrevocably.

M: So I felt like, they must be jealous also: that they never had this opportunity. (C14b)

Parents realized that if the sentiments encountered in deaf ecology persisted, it could have bearing on their child as well. Some perceived this as a risk of condemnation, as we discussed in the previous section. This risk would materialize most clearly if the child remained in the Deaf culture environment, some parents reasoned.

M: You feel like, where is this going if he remains at this [sign-oriented deaf] school? If he lives amongst those people who condemn him because he has an implant...(C14b)

Other parents hoped that the negative emotions would ebb away before their child reached adolescence.

M: I thought, before he really becomes a part of that world we will be fifteen years further. By then things will have subsided. (C12ab)

M: I think it will change once they [Deaf adults] see that it works. That it is sensible. I think that the resistance will become less and less. (C15)

Yet others argued against this fear and reasoned that choosing *against* an implant would imply an even greater risk of condemnation.

I: Are you afraid that he will condemn you [for choosing for an implant-ccw]?
M: No I would have been furious if my parents did nót give it a try He's my child, so chances are he will respond similarly Sure he may react differently, but if I were he I would have been angry if my parents did not do it. (C12ab)

Specific issues, cases and controls

The material discussed in this section did not highlight specific issues affecting specific subgroups.

Conclusions

Some parents perceived the modest information provided by implant teams positively, arguing that it would temper parents' natural enthusiasm. Indeed this assumption seems to be supported by the finding that quite some parents said that they were "instantly sold" on CI. Nonetheless it did not appear that parents were *blindly* positive, since some were rather well able to relativize the excessive optimism of the message conveyed by the popular media. Some other parents however, apparently would have desired somewhat more positive information, so to "convince" them given the controversy surrounding the procedure. This latter situation is also experienced in medical practice in general. If medical information is presented in too much detail and nuance, the authority is more or less displaced to the patient himself as the cardinal decision maker. In particular when it concerns controversial or highly emotional decisions, patients do not *always* welcome this situation. They are very much aware of the controversy and, given their decision to visit to the doctor's office, are pitched towards proceeding with a certain treatment even though doubts do remain. These patients sometimes seem to reason that further deliberation will not eliminate the uncertainty that surrounds the decision. What they desire from the physician is that he or she at least supports them in the decision or, alternatively, draws some of the responsibility related to this uncertainty away from them as decision-makers.

The fierce rejection of cochlear implants in deaf ecology troubled parents. As a result some parents started to evade discussion with opponents. Others came to question the legitimacy of their plans or decisions. Most parents however, seemed to question the legitimacy of the critique. By scrutinizing cochlear implant critique, parents debunk the

critique and redirect its arguments away from the direct well-being of deaf children. The critique was explained mostly in terms of a "conflict of interest" between the adult deaf population and young deaf children. Adult deaf individuals have little to gain from cochlear implantation, parents reasoned. The prospected benefit of enhanced spoken language skills has definitively passed them by. This in itself was postulated to yield a sense of envy. On the other hand, if cochlear implants are financed from a fixed budget, any investment into implants could imply less available resources for the things that do benefit the adult deaf population. Additionally, if implants would prove effective, they could theoretically limit the influx to Deaf culture.

Notwithstanding the fact that parents succeeded in relativizing the merits of Deaf culture critique, parents pragmatically acknowledged that the critique is very much alive amongst Deaf adults. They realized that if this situation persisted and if their child would become socialized in Deaf culture, he or she would likely internalize the critique as well. Understandable, this was considered a threat since it could imply that their child would come to condemn the decision to proceed with the procedure. Some parents felt however, that not choosing for an implant would entail an even larger risk of condemnation ultimately. In any case, some parents hoped that the negativity surrounding implants would subside before their child would reach adolescence - since this is the age during which socialization occurs.

MOTIVES TO CHOOSE FOR AN IMPLANT

Introduction

In the previous sections we illustrated what parents were told about cochlear implants and how they interpreted this information. In sum the information provided by implant teams focused strongly on the uncertain aspect of results. Deaf adults underscored this and added a parent-centered discourse much similar to that encountered in DC-ID, in the context of oralism and mainstreaming. Parents were critical about the euphoria in the media as well as the critique in deaf ecology. Notwithstanding this context, parents were "instantly sold" on cochlear implants. Apparently, analyzing the information provided *alone* is insufficient to grasp the deliberation process that parents go through. In this section we will focus solely on parents' story on why they actually did choose for an implant. All cases were asked this question explicitly and the issue was explored with them in depth.

Why parents chose for cochlear implantation

Asking parents about their motives to choose for a cochlear implant may be perceived as asking them indirectly about their expectations or hopes. When first asked about expectations, most parents appeared to repeat the modest message conferred to them by the implant team. They spoke for example of 1) breaking through the silence, 2) improving understanding of the world around, 3) environmental sound awareness and 4) traffic safety. Remarkably, not a single parent spontaneously mentioned "spoken language" as a cardinal goal.

A large number of parents mentioned "environmental sound awareness" as the primary motive to choose for a cochlear implant.

> *I: Do I understand you correctly, that the most important thing to you when considering an implant was not so much her ability to speak but to regain a world of sound?*
> *M: Yes, that she would be out of the silence (C1a)*

> *I: Why did you choose for an implant?*
> *M: So she would have some hearing...completely nothing is so much "nothing" you know. (C2b)*

On the one hand this issue appeared strongly related to the "exemplar of silence" that we discussed in chapter three and which we also encountered in the way the popular media portrayed (adult) cochlear implantation. Indeed, one parent actually made reference to the testimony of post-lingually deaf implant recipients.

F Yes, I think that it breaking through the silence, the absolute silence Look a child with some hearing remains well it at least hears something But if you hear nothing at all that is of course I know that others may say is that worth so much money? Well, I don't know but if you can hear a car, you can hear a bird You can perceive sound So those environmental sounds ehhh, you hear something But ehhh, there are a few adult deaf people with an implant who have written about "beyond the silence" and such ehhh (C9a)

As we stated in chapter three, the narratives on silence appeared to represent a somewhat diffuse concern originating from linking silence to suffering, common to our prejudiced view on deafness

I You did not think about him possibly speaking again [with an implant]?
M I hoped it would improve [ ] if he would catch more sound, learn to control his own voice sure that was an added benefit, but the isolation was our chief motive (C12ab)

For parents of children who became deaf as a sequel to meningitis the agony of silence was also derived from the sense of loss, since their child had previously heard (C9a)

M She was a hearing child and suddenly her world turned completely silent We noticed that she missed that [ ] To give her some of her hearing back She used to be just a regular child and from one day to the other she could not hear anything at all except vibrations [ ] She was hearing and suddenly became deaf If only we could give her some hearing back (C1a)

Yet as we also discussed in chapter three, the issue of environmental sound awareness is related to the fact that environmental sounds are an essential part of the world of the hearing Being aware of these sounds was hence related to being more "connected" to the world around

F Becoming aware of sound - separate from language we stress - is a factor of benefit which has been underestimated Why it is of so much importance? We had a deaf child and when he would be playing in a corner of the room he would not look away unless a truck would pass by, as it would cause the house to shake That is when he would notice something happening Or if the door would open or the light would be turned on Besides this, he would notice nothing really When he got his implant, we noticed that he became much more aware of the world around him If his brother would walk in the room crying for example he would just continue playing before he had the implant Now he will notice and turn his attention to him Normal contact yes He just gets so much more information, not because he listens better, but because he is much more involved (C5a)

M Animals too He is an outdoors person and it would be nice if he could hear the animals We keep sheep When they make sound, wouldn't it be beautiful for him if he could hear that? (C8b)

F: I recall an incident this morning. She was waiting for the taxi and we were looking at birds. Suddenly she said: "I think I hear the birds, they do peeppeeppeep right?". And she was not even wearing her implant So I thought, thanks to the implant, that idea has grown. There are little animals, birds, flying around and they make sounds. I really enjoyed noticing that, that she realizes it, that it exists. So I plan to take her into the woods soon, when the birds are singing really loud. We will go into the woods with her wearing the implant. [...] But also other sounds like the sea or an airplane or mumbling in the classroom. That provides color to her view of the world around her
M: It makes it more logical
F: It gives her orientation points so to say. (C13)

The value of environmental awareness was verbalized particularly eloquent by one parent dyad, who seemed to desire a symbolically unified world between them and their deaf child.

M: It gives you something to share. Like last week he was walking outside and starting making this sound. So I walked up to him and he told me: "I hear this sound...". It was the chirping of the birds. That made me think: "isn't that beautiful?". For us it is a beautiful sound, yet he doesn't know what it is yet
F: No, for us it is rather normal that a bird sings, but it isn't for him. (C8b)

Finally, for some parents environmental awareness was placed in the context of safety, more concretely safety in traffic.

I: Was her poor speech a reason to consider cochlear implantation?
M: Well, I do not know. If she can hear something, that would be nice. Especially on the street, for the dangers on the street. I feel that is important. Environmental sounds, so she can respond. (C10ab)

F. We hoped that she would come to capture environmental sounds better, on the street and such. (C15)

M: Also from a practical perspective I felt like if he rides his bike and can hear a car horn, if only he could hear that. That makes a difference in safety terms. (C12ab)

F: And specially for traffic safety.
I: Is that a problem?
F: I think so. I meet him regularly, he just crosses the street right in front of a car...(C3b)

F: You know, he will have to go on the street and so on.
M: And he will encounter cars, bikers, and motorcycles.
F: It would be nice if he could hear something on the street, that he can hear traffic coming. Even if he can only hear a car, we would be very content. (C8b)

Yet it appeared that for most parents the issue of environmental sound awareness was *not* the cardinal motive to choose for an implant. Despite the fact that implant teams did not

encourage parents to think beyond some environmental sound awareness and perhaps improved speech, parents confessed that their "hopes" went beyond this

> *M You have secret hopes that it will yield more in spite of the negative tone [of the implant team] you keep that (C12ab)*

> *F There is an emotional side to the decision You know, even the smallest sign of hope is enough [ ] You just take everything that crosses your path That is rather normal I think (C7a)*

If asked explicitly if environmental sound awareness was sufficient to legitimize CI, many parents (apart from C8b and C6) eventually responded negatively (C1a) As such, parents seemed to use the environmental sound argument to "conceal" their appreciation of spoken language skills This may have been the result of tempered expectations in the information process (Blume & Yardley, manuscript), the moral dismissal of spoken language in deaf ecology or "narrative reconstruction" if the child had not (yet) benefited from implants in spoken language terms

Parents clearly hoped that the implant would improve their child's speech quality

> *I If I would have informed you back then and told you that perhaps she can hear traffic with the implant Would that have been sufficient?*
> *F It would have been a start*
> *M No, but we felt that she does not hear anything and it may support her in her speech because she can hear herself That was our idea (C2b)*

> *M We hoped that it [speech] would become a little better a little more intelligible (C3b)*

> *I If I would draw this picture for you Let's go back in time some five years before she was implanted You would ask me I have heard of CI can you explain to me what it is? And I would say 'Well, cochlear implantation will allow a child to hear environmental sounds to hear traffic But she will absolutely not be able to speak better as a result' Would you have chosen for an implant?*
> *M Well no I really enjoy that she can make herself understood and that she can hear things Language development that is the most important I feel (C10ab)*

It was hoped that the "feed-back" that implants provide would improve speech quality

> *F We learned that cochlear implantation would lead to recognition [of one s own speech] That was the largest benefit of CI to be able to hear what you speak (C7a)*

> *M It is so important for the use of speech if you can actually hear you own speech or not (C14b)*

> *M It is crucial that she can hear herself Her own voice [ ] that makes it easier to learn to speak (C2b)*

F: I think it will aid in attaining better speech, because it provides a feedback loop and can hence better learn to use her voice. (C3b)

Being able to hear speech cues by others would facilitate lip reading and communication, parents reasoned.

F: Lip-reading and speech are facilitated I think. (C3b)

M: I imagined that the implant would allow him to hear a little and if he would hear maybe he could come to speak. (C16b)

M: It is just easier [to learn speech] if you have access to sound, you will learn it easier than without it. (C1a)

One parent, whose child did not develop any speech at all, was outspoken about her motives to implant.

I: Look, we did not expect that he would speak right away, but we did silently hope that he would come to speak eventually. But he just does not [speak]. So you ask yourself what you did it for. If you look back and ask yourself what you did it for: only for sounds that he catches outside or in the house? (C16b)

Without any perception of sound, development of speech and language was considered close to impossible. Yet, with some hearing the process would be facilitated considerably. Parents derived this assumption from their experience with children with lesser degrees of hearing loss, as we described previously. They learned this through deaf school experience, where they noticed how children with lesser hearing losses attained language production sooner and better.

F: We noticed differences [in spoken language acquisition] between children with and without hearing remains. [...] The girl I was talking about earlier, she had hearing remains and did start to speak.
M: We also noticed it at our communication course. We were the only parents with a truly deaf child and you really do notice the difference.
F: Yes, we heard parents say that their child could still hear.
M: Like, he still can hear an airplane or truck, but our child did not hear anything at all.
F: He was tested up to 110 dB, because they did were afraid to go any higher. So we thought, taken all that into account, that with cochlear implantation his hearing would perhaps improve to a level, like...that is what we thought. (C14b)

M: You notice the difference between someone who is hard of hearing and can still do something with hearing remains and someone who is completely deaf.
I: What difference?
M: Better speech, easier to learn if one has hearing remains. [...]. We noticed ourselves that there is a large difference between hearing nothing at all and hearing a little bit. (C1a)

F: The advantage of it [CI] is that one gets below a certain threshold, which has a positive influence on speech. If you go from 110 dB to 70 or 60 dB that would be quite some gain. (C7a)

F: Look, if one observes the statistics, it would have been much better if he were less deaf than he is. That would have changed things. But his hearing loss was similar to John [fictitious name-ccw] and we experienced that he did very little...(C8b)

F: One thing we noticed, which is also important in the context of cochlear implantation. Each time that we would visit class we noticed. hey, those children can speak quite well. When we confronted the school with this observation they would always respond by saying that those children had some hearing left. [...] It also showed in videotapes that we had seen. When we would remark how well those children did speak, it would be argued that those children had some hearing left [..] So, we became more and more aware of that distinction. For a profoundly deaf child it is very hard to acquire some spoken language, unless súper talented [...] We felt that if our daughter would not get an implant she would never learn to speak. That was a main motive for us I think. (C9a)

Parents also concluded that since hearing aids were so much advertized in deaf school, the benefits of implants followed logically (C7a). The advocacy of hearing aids by deaf school personnel was seen as theoretical support for cochlear implantation.

M. I thought it was strange. When you get a deaf child, they want them to wear hearing aids the very next week, so they can take hold of some sound. So they can hear some sounds, to improve their understanding, to facilitate speech recognition.
F: The auditory nerve needs to be stimulated.
M: The auditory nerve needs to be stimulated. But when it proves that your child does not comply in these terms and a cochlear implant may help, hearing aids are OK but an implant is not. (C14b)

F: Because they insisted on hearing aids so passionately in deaf school. Because everyone has sóme hearing remains and those remains help in learning to speak. (C9a)

Yet the value of spoken language skills went beyond these skills in themselves. Spoken language skills were postulated to facilitate functioning in the hearing world.

I: The implant team told you that you should not hold high expectations. What were your expectations, of let's say when he is about 20 years old?
F: I would not know
M: I think that he would be integrated easier in society, between hearing people. (C14b)

I: You have told me that you valued cochlear implantation because it would facilitate her awareness of environmental sounds, hearing cars and so on.
F: Yes.
I: Was that the core reason for your decision?

M: Well no. More so the hope that she would be able to [succeed] easier in the hearing world. How do you say that?
F: Well I think it was our basis, plus that we were convinced that a deaf person has to be able to stand on his or her own in the hearing world. (C15)

F: We have more than one reason for it. We chose for cochlear implantation to optimize his chances to function in hearing society: to improve that. To improve that implies that he would have to improve his speech. [...] Those two aspects are of importance. (C11)

As such parents perceived of cochlear implantation as an "instrument" or "tool" to lower the threshold of hearing society for their child.

F: It is a useful tool. Just like a toothbrush is in cleaning one's teeth, this thing is useful to learn how to engage in the hearing world. (C13)

F: We perceive of it as a tool really. (C15)

As we discussed in chapter five, to invest in a child's ability to function in the hearing world was perceived in favor of his or her best-interest. Parents argued that they would make use of *any* opportunity to enhance their deaf child's future opportunities. The reason to decide positively on cochlear implantation was hence strongly related to the child's future best-interest: congruent with Christiansen (in press) we found that this was a major reason why parents chose for a cochlear implant.

M: I feel that one has to seize ány opportunity that enhances her chances. (C10ab)

M: It is about her future really, about what is best for her in the future. (C1a)

M: I thought, regardless of what the Deaf were saying and in spite of how much I respect their language and identity: I want to try to give her the best of both worlds. If cochlear implantation can contribute to that, that would be very nice. [...] That [the Deaf world-ccw] is her world and the world we wanted to get to know. That is why we learned Sign language etcetera. But at the same time this is our world and the world of her sisters, her neighborhood, the school. And this [spoken language-ccw] is our language, the language of which we are proud. If possible in any way, we would like her to feel at home here. (C13)

More outspoken than previously parents acknowledged their preference for the hearing world.

M: I wish that he could hear so much with the implant that he will succeed in the hearing world. Because it is my world too, the world I understand best. (C11)

Still, many parents realized that their choice for an implant could fail in the future.

M: Maybe in five or ten years time she'll come to say: "I think cochlear implantation is stupid. I will just proceed in life with Sign language. Forget about it, I am putting the implant away." (C13)

Parents accepted this risk and advocated flexibility to accommodate their child if failure occurred. This flexibility to deal with unexpected outcomes is in line with how we described parents' attitudes in previous chapters (Reinders 2000).

F: We are not the kind of people who buy a lottery ticket and think: "Well, we are going to win the jackpot". No, we are more modest. [...] Of course we hoped it. That he would learn to speak like us. But even half of normal was OK. But it is not like you expect that. (C3b)

The ultimate "test" would be continued use as an adult. Parents realized that their child could stop using the implant at some point and felt that this would be the result of inadequate benefit. Thus some "minimum" benefit was considered necessary for prolonged implant use.

M: If she will at one point say, "I do not want it anymore" we will stimulate her But such an event would result from not enough benefit. (C10ab)

Parents said that they would respect their child's choice to discontinue using the implant at some point. Parents felt that "at least they had tried". Additionally, they reasoned that in the worse case ex-plantation was an option (C8b).

M: Too bad [if the child would reject CI-ccw]. It can always be explanted, that is not a problem at all. At least we kept all options open for her. That was our objective. [...]
F: If she would ask us why we put her through it, that "stupid cochlear implant that I do not use and only bothers me". We would say: it is a one-way decision, you either have to do it now [at early age when child cannot decide-ccw] or you never do. Of course it can be reversed later. But you cannot not do it now and do it later So it is a gamble, a gamble that we took. Based on the knowledge available to us then we did the best we could. (C13)

As such parents upheld the moral value of self-determination. The fact that an implanted child had the right and possibility to stop using the implant at an adult age was perceived as a strong counter-argument against critics who claim that parents nullify choice through implantation.

F: I do allow him to choose. Later, when he is 18 or perhaps even younger He will be able to determine if he wants to hear or not. If he does not want to hear, he can discard of the implant and he will be just deaf and can get along in the Deaf world If he does not want that, he will be able to use the implant (C14b)
M: You just explain [to teachers at deaf school-ccw] that you try to do the best for your child. And that the child will be able to choose when older. We offer her Sign language and we offer her cochlear implantation so she will have some hearing. So our child will be able

to choose, like to enter the Deaf world or the hearing world So she can choose herself (C15)

M They [Deaf adults] charge at CI That it is gibberish That the child should be able to choose But I feel that every child has its own story It is different for everyone So I think 'Do not judge us us hearing people who feel that she benefits And she is allowed to choose maybe she will and I will have peace with that She can go two ways (C4ab)

While parents were willing to accept failure, failure as the result of "peer pressure" (rather than inadequate benefit) was not valued

M She will have to determine that [benefit] herself after some time But not because of Deaf culture, like we are deaf and we do not want any aids I would not fancy that (C10ab)

Parents of older children realized the potential of peer influence in adolescence however As a result several parents conveyed that they perceived of adolescence as a potential problem, in particular if their child would not succeed in transferring outside the deaf educational system in time The deaf high school educational system was perceived as the cradle for Deaf culture Once in this environment, the child would risk to be pushed into the direction of a unique Sign language existence Parents also realized that as the child becomes involved with his or her identity and the relation thereof with the social environment, this changes the social context Young children with an implant may be "naively spontaneous" in their use of spoken language

F Even though she is sometimes hard to understand, she keeps trying Even if she had to repeat herself 20 times, she still engages in conversation with everyone whom she meets Complete strangers too (C7a)

The implanted adolescent however will become more aware of the things that set him or her apart from others namely the implant itself and the marginal communication skills Parents often realized that this new social context could induce a retreat into Deaf culture

F At a certain moment a phase will come when they will feel embarrassed towards the hearing world This can turn them away
M That is a rather scary phase It is said that their speech that they start to speak less because they feel that they speak funny" This is a phase during which one really has to motivate them, like 'do your best" or else it will just fade away (C7a)

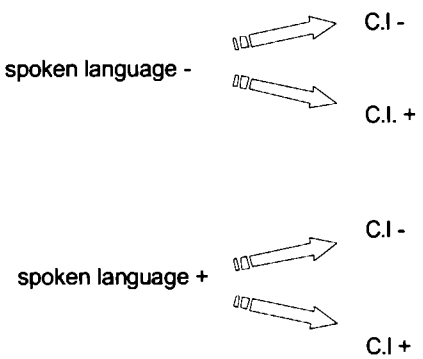
Rejecting aids, as a part of one's "identity" or "culture" did not trigger much sympathy

M Sure an implant is different than a hearing aid, it is quite a procedure But I feel that if one has a disability one should reach out for the aids available to make one's live a little

better. You have to seize to opportunity The Deaf culture position does not appeal to me. (C10ab)

Specific issues, cases and controls

We argued that enhancement of spoken language was one of parents' prime motives to choose for cochlear implantation. Could it be that an individual child's actual progression in spoken language terms influences the decision for or against cochlear implantation? In theory four models are possible:



If spoken language fails to develop to a satisfactory level, this may prompt parents to choose for a cochlear implant to "rescue" spoken language so to say. One could hypothesize that this mode is relevant particularly for parents whose child became deaf after he or her had mastered some spoken language (C3b). Indeed three out of four cases that fitted this description were the parent of a child deafened through meningitis (exception C14b).

I: How was her speech when you considered cochlear implantation?
M: Not much at all. We were not happy with it at all.
I: Did that concern you?
M: Yes it did. (C10ab)

F: He never used his voice at all. Before his implant maybe he wanted to say, "ape" but he just had no clew that he had to produce sounds. We tried to and he tried very hard. I just felt like, if only he would hear something, he may come to use his voice. (C14b)

M: You could just see it get less by the day.
F: Yes. Six weeks later and it was all gone. All gone. So we have always said: we have to do something with it. (C9a)

Yet the lack of spoken language development could also prompt parents *not* to option for a cochlear implant, since they may perceive the lack of language as a sign of the futility of any attempt to teach the child spoken language. Two controls clearly represented this idea. Deaf school personnel may have stimulated this perception as the somewhat vague concept of "language sensitivity" is used abundantly in the evaluation of deaf children.

> *M: So you compare. We have other children as comparison and that does play a role If they [school staff] would have indicated that she could become proficient in speech [it would have been different-ccw]. But it was absolutely impossible for her. So that is what you navigate by. (CO6b)*

> *M: You can train his speech 8 hours per day, but he will still fail. You have to be realistic. [...] I would be crazy to do something of which I know in advance that it will fail. You should realize how heterogeneous the group is. You are dealing with differences in intellectual capacities. You are dealing with language sensitivity It is a definite pre if your child is sensitive to language. And there are children that are dyslectic. The group is very diverse (CO1)*

Similarly if at least some spoken language develops in spite of profound deafness, parents may perceive this as a sign of the *intrinsic* capacity of their child to develop spoken language, which may prompt them to seek cochlear implantation to facilitate this process.

> *M. He was still talking. I hoped that it would improve with it [CI]. (C12ab)*

> *M: Before implantation she was making headway with speech as well. I think she would have learned to speak but it would have taken a longer time. (C2b)*

Alternatively, spontaneous development of spoken language may convince parents that they can realize their goals *without* resorting to cochlear implantation. The deaf children of CO3 for example, both of whom had some hearing remains, had managed rather well in spoken language terms without a cochlear implant.

> *M: He does so well with his hearing remains that I do not dare to implant him, to put an implant in there: because you will break a lot of structures. (CO3)*

Conclusions

We found that a surprising number of parents mentioned environmental awareness as their primary expectation when deciding for a cochlear implant. This finding is congruous with Kelsay who reports that 89% of parents mention environmental sound awareness as the expected benefit at the pre-implantation stage (Kelsay 1996). Improved speech perception and speech production scored significantly lower, 50% and 36%

respectively. Yet we suggested that on further scrutiny it appeared that the latter two aspects *were* of significant importance to many parents, be it not in the form of a concrete expectation but as "hope". It therefore appears that parents temper their expectations of spoken language acquisition. This may be for several reasons. First of all parents were explicitly told that they must hold only modest expectations. Hence it may, as Blume and Yardley have stated, "reflect the realism of the professionals" (Blume & Yardley, manuscript). To attest that the decision was made to acquire spoken language would go against this advice. Furthermore, to aim at spoken language in itself has become a questionable goal as we have argued previously. This may also prompt parents to conceal their desire for spoken language. Finally, the wish for speech may not so much be depicted as a rational goal but a "compelling hope" as Blume and Yardley have stated (Blume & Yardley, manuscript). It was striking that in particular parents of children that did not (yet) attain spoken language spoke about "secondary" motives such as environmental awareness. It may be that they did because they genuinely feel that aiming for speech is controversial. This in turn could induce an under-challenging environment, which is likely to lead to mediocre progress in spoken language terms. It may also be however that parents utilize secondary motives to avoid disappointment, both for themselves as well as the direct environment. However, it remains complicated to attribute a hierarchy to parent's motives. One may be inclined to hypothesize that spoken language stands higher in hierarchy and that parents mention other motives first because they are familiar with the controversy around oral methods in relation to cochlear implants. It may well be that the current context of the cochlear implant debate leads parents to focus on environmental sound more than they perhaps would otherwise. Defining the benefit of cochlear implants in terms of spoken language skills is controversial. For Deaf organizations this may possibly be explained by the reminiscence to oralism and the potential implications it could have for Deaf culture. On the other hand the motive of "breaking through the silence" impressed as genuine indeed.

Kelsay and colleagues report a shift in reported expectations as time elapses (Kelsay 1996). Three year post-implantation the benefit of environmental sound awareness was ranked down from first to third place: it decreased from 89% to 61% while the benefit of speech perception increased from 50% to 78% and the benefit of speech production from 36% to 74%. This response shift may be perceived as support for our hierarchy thesis. Response shift, distortion or recall bias are established phenomena in prospective studies (Mancuso 1995; Herrmann 1995). Adang and colleagues have published on a seminal study in this respect (Adang 1997). Prospectively studying a cohort of 22 insulin-dependent diabetes patients with end-stage renal failure, they found that patients were inclined to retrospectively score their quality of life prior to kidney-pancreas transplantation considerably less favorable than they did before the transplantation. The concept of "response shift" is however likely to be subliminal. It may either represent a coping strategy to deal with certain life events which are fixed (such as chronic disease) or be the result of the much cited claim that people who live by certain standards for years adapt and find new purpose in their circumstances (Wever

1997). Indeed Casileth found that patients with chronic disease do not differ from healthy people in how they judge their quality of life (Casileth 1984). Finally, the post-operative negativity about the pre-operative situation may function as a support for the decision that has been irreversibly taken. A persistent positive report on the past would imply question surrounding the success of the decision to transplant. Yet in the case of cochlear implantation a third issue should be considered. Given the fierce rejection of implants and the real chance of failure, parents may indeed only be complying with what they believe is expected from them. Parents may hence supply us with "socially desirable" answers. Perhaps "genuine" hopes and preferences emerge only after a child actually succeeds in spoken language.

MOTIVES FOR NOT CHOOSING FOR AN IMPLANT

Introduction

In this section we will analyze what our controls had to say about their decision not to proceed with cochlear implantation We note however that in retrospect we found that most controls spoke remarkably little about cochlear implantation, even though the discussion was directed at that specific topic on several occasions during the interview Parents spoke little about the option of cochlear implantation in their concrete context and also spoke little about what they thought of the procedure and the social discussion it had triggered Additionally, with the exception of one parent, the narratives on cochlear implantation were generally not negative in tone The bulk of these parents' story focused on the general issues that were discussed in the previous chapters

The non-choice of cochlear implantation

One critical finding was that a majority of controls never really made a decision against cochlear implantation In order to speak of a "decision" it appears that at least the following requirements should be met 1) parents should have been aware of the procedure, 2) from what parents "know" it should be clear that their child is also "suitable" for the procedure Our material showed that 4 out of 7 controls did not meet these requirements Two controls were the parents of children who, because of their advanced age, never had an option to choose for cochlear implantation (CO3, CO5) Additionally CO5b had some hearing remains, which at least during the early days of cochlear implantation excluded the child from implantation

I Was cochlear implantation ever a topic for you?
F No
M He has some hearing remains In the beginning period they only implanted children who had no hearing remains at all children who had nothing to lose So it never was an issue because he had hearing remains
F It was primarily for post-lingually deaf people back then (CO5b)

M It was not an issue It came too late, in Belgium and the United States also (CO3)

CO5 was first informed about cochlear implantation when their child was about 8 years old These parents chose to refrain from implantation, because their child was making good progress in general and had decent command of spoken language

F It implied that he would have to take a leave [from school] and that we would have to start the process all over again So we would have to disturb the process that was going so

well [ ] Uncertainty yes The time that he has to be in the hospital to recover He is delayed as it is and this would only delay things more Having to learn to hear again making use of the device That would delay him That could cause him to miss contact with his friends [ ] He is at a critical age almost in adolescence That was important for us not to urge things (CO5b)

Had the choice been available at a younger age, this couple attested that they would have considered CI

M Yes we would have considered it In particular if his speech development was worse than it was If it were available when he was younger we would have considered it (CO5b)

For an additional control the choice never really presented itself since her deaf child had hearing remains (CO7)

M They [deaf children-ccw] were a little older so And they have some hearing remains so they were not eligible In fact the choice never occurred It never was a discussion here (CO7)

Another control did actually apply for cochlear implantation, but the child was found unfit because of unknown reasons (CO4b)

This implies that four out of seven controls never actually got to decide for or against cochlear implantation Of the remaining three controls, one parent couple applied for cochlear implantation but withdrew voluntarily during the selection process (CO6b) The other two controls never explored the possibility of cochlear implants to the level of actively seeking out information As such it seems fallacious to speak about a "choice" against cochlear implants in this regard Notwithstanding this fact, all controls did hold opinions on cochlear implantation, which we will include in this section

Questioning the feasibility of cochlear implantation

In the section on deaf ecology we defined two forms of cochlear implant critique critique at the level of construct validity and content validity Construct validity seemed to be the most dominant reservation that controls held about cochlear implants Perhaps more so than cases, controls were rather *skeptic* about the feasibility and efficacy of the technology Especially for parents of older children, for whom cochlear implants became available during the initial Technology Assessment phase, the "experimental" status was an issue During this period, the cost of the initial Dutch assessment trial was financed through the national fund for investigative medicine The word "investigative" in this context refers to clinical trials in general Parents felt reluctant to expose their child to a technique, which they considered insufficiently researched

M: We felt like it was similar to pacemakers. Let them first implant 2000 children, and then we will apply for our child. (CO3)

Furthermore parents questioned the causality of the reported results. Some parents reasoned that not the implant but rather natural progression or the stimulating rehabilitation environment (CO3) was responsible for spoken language progress. One control, whose children had mastered spoken language, also argued:

M: They do make a spurt in their language development from the age of 12 you know And it continues into their twenties. (CO3)

Another argued that the intensive speech therapy that implanted children receive likely co-explains the advances in spoken language skills.

M: If she is implanted, she will get it [speech training] six times per week. But if she is not you can forget about that· three times per week at the most. (CO6b)

This issue has been raised by others as well and has been the zero hypotheses of some linguistic inquiries in cochlear implant results. As a matter of fact, one of our controls participated in a study comparing implanted and non-implanted children in a setting where both are offered the same resources.

M: We offered that she would be a "shadow child"
I: What is that?
M: A shadow child implies that, they compare a shadow child without an implant with an implanted child in terms of achievement. That is a study that is going on. In how far they are synchronous. Because it is not a surprise that if one gets speech training six times per week that it [spoken language development] will proceed smoother than if one gets training three times per week. (CO6b)

Thus, *faith* in the potential benefit of implants was a determining factor. One control underscored this verbatim.

M: That [faith-ccw] is determining for one's decision. Like at a certain time one has to decide If you have faith that implants will be beneficial for her in the future, one is likely to choose for it. (CO6b)

Yet, inversely, faith in the limited liabilities of implantation was also an issue. Controls seemed to worry more intensively over the potential dangers of the implant procedure. Some parents worried about the physical impact of implants. For one parent (CO3) this was the determining factor.

M: We know so little about the effect. Sure, that it allows more sound waves through is clear to me. But what else does it do? (CO7)

M: With cochlear implantation you know that you are going on an experimental journey. And you pray to God that it does not destroy more than is already broken [...] How will it be ten years from now? Will there be scar tissue? Uncontrolled cell growth? [...]
I: If your children did not produce any spoken language [which both did-ccw], would that have changed your position? Would you have considered cochlear implantation then?
M. No. I just do not dare. What is the implant going to do after so many years? I find it creepy. Do you ever have to do the operation again? Will there be failures? I do not know. (CO3)

One parent believed that it was important to keep the inner ear as intact as possible, since genetic engineering would likely provide a more definitive solution in the future.

M: Imagine that genetics finds something, that you can cure it What are you to do then [if the child was implanted-ccw]? I strongly believe that it [genetics] will be a factor in the future once politics supports it. The development will be extremely rapid. (CO3)

Some parents seemed to base their skepticism on "empirical" material, though the empirical basis was based on casuistry of hearsay primarily since none of our respondents were actually aware of clinical trial results. Some parents felt that implant results were rather meager, something that was based on experience with a few implanted children. CO3 was strongly influenced by one well-documented implant failure. CO6 withdrew their child from the selection process based on a single implant failure.

M. From what I have seen so far the results are rather disappointing. (CO3)

Potential psycho-emotional liabilities of cochlear implantation were also raised. This concern was very similar to the liabilities of oralism that we discussed previously. More so than cases, controls worried about the psycho-emotional impact of cochlear implantation. The lack of long-term psycho-emotional data has been one of the main points of criticism with which Deaf organizations successfully lobbied for a freeze of funds in the 1990s.

M: I know that about 80 children have been implanted and that they know little [about the results-ccw]. And I also read somewhere that Els Borst [Dutch minister of Health] feels that the emotional and social aspects on the longer term are not known, that is why she decided to freeze funds. [...] I think it is an illusion to think that children will hear with an implant. [...] They cannot use the phone I have heard. (CO2)

From the excerpt above, it appears however that this factor does not stand alone, but should rather be perceived in light of the anticipated benefits: benefit and liability form a rather powerfully associated pair as we will discuss in the final chapter of this thesis.

A specific liability that we did not encounter as such previously, was the physical limitations that the implant device would bring about. Some parents disliked the idea of an implant, since it made their child dependent on technology.

M: You will always have to walk around with that thing around the ears and wearing the speech processor. It is yet another impediment. With sports too. (CO3)

Upholding the cultural approach

The second line of critique referred to content validity. This roughly implies that the aim of cochlear implantation itself is brought into question rather than feasibility issues, though it seems illogical to separate the two categorically: low expectations for success are likely an important prerequisite for this form of criticism. Some parents perceived the status of deafness as beneficial and preferable over hard-of-hearing. Law protects deafness more so than lesser states of hearing loss: profound deaf individuals have more resources available to them. Some parents feared that with an implant their child would be categorized as hard- of-hearing while still much in need of special aid, such as Sign translators.

M: Imagine that the audiogram would reveal that he is no longer a deaf child and we would lose all those rights. What are you to do then? You lose so much But nobody mentions that. The information campaign does not mention that you have rights now but may jeopardize them in the future. Now you have facilities and then you will have to do with other facilities. Of course there are facilities for hard of hearing children, but a Sign translator for example is not available for the hard of hearing. You may have the machinery but will have to do without all those services available for the deaf. In our view the deaf are better off in this sense, they have more facilities. (CO6b)

Some parents seemed to prefer the *clarity* that Sign language provides: Sign language was valued *because* it externalized the disability, thereby avoiding potentially painful confusion. An implanted child is likely to develop some speech skills yet not enough to communicate effortlessly in the hearing world, parents reasoned. Yet by using speech the visibility of handicap diminishes instantly, which may yield a less considerate environment.

M: I think things will become more difficult as one learns to speak better. People will be less considerate of the handicap: because you won't notice it anymore. If people ignore the handicap, one will become extra handicapped. (CO6b)

One parent was particularly decisive in her views as she rephrased the issue in terms of "identity".

M: Cochlear implants are confusing the issue of what your child really is. Does the child become hard of hearing because it has gained some speech ability? You end up in a gray area, so I can imagine that parents sense identity problems, like to which group does my child belong? I think that is rather painful. (CO1)

Parents also feared that, notwithstanding possible advances in spoken language skills, an implanted child would risk failing to find a socio-cultural environment in which he or she can thrive, an issue that was also raised at the Nunspeet meeting (Van Lange 1996)

> *M If you look at culture, they may fall between two worlds That seems appalling to me If we aren't careful, they won't fit anywhere*
> *I How is that?*
> *M Well, because the Deaf world does not perceive of them as deaf And the hearing world will not see them as hearing Because evidently they still need that device and they still talk funny (CO7)*

Apparently parents felt that implant results would most likely not be sufficient to allow the hearing world to provide in this respect Given the fierce antagonism against implants, acceptance in the Deaf world would also be seriously at stake

> *M You worry about if she will be accepted as human being You worry about that because you sense so much resistance in the Deaf world (C15)*

In one parent a profound resistance against medical procedures dominated the choice against an implant This mother had experienced the meningitis period as severely negative

> *I If you think about cochlear implantation, how does that make you feel?*
> *M Do I have to answer that question? I sublimate it, like so many other things I do not want to think about it*
> *I Why not? What image comes to mind?*
> *M More white coats, hearing doctors who mess with my child Hands-off! (CO2)*

Specific issues, cases and controls

From the above it could appear that cases did not experience liabilities They did Cases shared many of the concerns raised by our control population

Indeed the cochlear implant "externalizes" physical functions, most importantly through the presence of the implant headset Some parents perceived this as a liability

> *M The child will always have to wear the equipment That is no fun, that external device [processor], the whole thing (C10ab)*

> *F I disliked the idea that it would limit him as well He would have to be more careful, which he is not It is expensive equipment and the processor is so large [ ]*
> *M He would not be able to do certain things, like jump in a pool in the summer or going down a slide I feel that is limiting*

F He cannot play around when it is nice weather, he cannot do that with the equipment (C8b)

One parent based her opinion on a widely read autobiography by French author Emmanuel Laborit (Laborit 1994)

M Based on the book by Laborit a French woman I can ask myself like it is a breach of her integrity the integrity of a child As parents one may think we have to get her operated' but you do put a screw in her head because something is wrong That sentiment was really strong in that book (C13)

Fear for psycho-emotional liabilities was also expressed

I Can you say something about your deliberation?
M Deaf people who have been raised orally have so many emotional problems when grown up So that makes you think What am I doing to him imagine that he will get psychiatric problems' We were afraid that we would get a less happy child back in return He was always so happy and you fear that you'll get a child back who is introverted (C2b)

Put against the low expectations of CI, indeed some parents had trouble to legitimize the elective procedure that cochlear implantation is Some cases also struggled with this issue (C6)

M It was necessary from our point of view but it wasn't like they were going to remove a lump or something She wasn't going to die if we did not operate her (C2b)

Yet others relativized the risks of the procedure, and as such reached a different conclusion

F Well, sure it is an operation - and a rather large one But it is not a dangerous procedure They do not actually enter the head They restrict the procedure to the cochlea It [hearing] can only improve not deteriorate (C3b)

As we have shown, some controls seemed to value Sign language for its ability to make the disability "visible", which is postulated to prevent misunderstanding in the interaction with hearing people One case argued against this however or, more accurately, provided the limits of the argument

F It is strange really, she is deaf but she is not That is because the implant When she wears it she is hard-of-hearing when she does not she is deaf
I What is the difference between the two?
F For others it is confusing When I tell others that our daughter is deaf, I am afraid that they will not engage in communication because they do not know how to [ ] People do not know how to deal with someone who is deaf [ ] There is this barrier, like How do I communicate with a deaf child I do not know sign Does the child sign? (C4ab)

As we illustrated, some parents were especially outspoken about the desirability of identity- and cultural-clarity (CO1). One case refuted this idea however, arguing that there is no compelling reason why Deaf culture should reject implanted children. If someone was to be blamed, it was the parent who ultimately decided for a deaf child.

> *M: Well, he can always blame us. After all we were the ones who got him the operation He was only five and had little say in it. So he can play innocent and throw his implant away. I cannot imagine that the Deaf world would not accept him. They could not accept us [because of the decision to implant-ccw] but that is much less of a problem. [...] As long as he gets accepted. (C12ab)*

Another parent suggested the option of a *hybrid identity*. Rather than positioning implanted children in "no-man's-land", this parent visualized an enriched situation where the child could come to function in both worlds.

> *M: So she said: "now I have an implant and I will learn to speak". I responded by saying that it would not be that easy. And she said. "yes, but I want to be a bridge between your hearing world and the Deaf world and I will carefully pick people with whom I want to engage from the hearing world". She signed: "here I am with my implant, this is the hearing world and that is the Deaf world and I am in the middle". That is very beautiful. (C13)*

Though this parent attributed this statement to the child herself, it seems more likely that others handed the child (only 4 years old) this image (Bertling 1998).

Conclusions

Perhaps the single most important finding in this section is that 4 out of 7 controls cannot be considered to have chosen against cochlear implantation really. Nonetheless many controls had something to say about cochlear implantation. Reservations may be organized as congruent to construct or content validity. Construct validity reservations were paramount. Control parents perceived of implants as "experimental medicine" and felt that much more research needed to be done. Experimenting with children is something that is likely to stir emotions, particularly if the word is interpreted as experimenting for the sake of science.

> There are things that do not sound very attractive, like "experimenting with children". Still more unattractive is "experimenting with children who will not benefit from it", the non-therapeutic experiment (van Veen 1993 – translation ccw)

In general *faith* in positive outcome and limited negative outcome was lower in controls as compared to cases. Control parents worried about the potential physical damage implant surgery could instill. They also worried about possible psycho-emotional

liabilities and the physical dependence that implants entail. Based on hands-on experience, these parents also felt that implant results were rather limited. In addition they questioned the causality of implant results. This strengthened them in their conviction that it was not worth the risk. Parents felt that implants were unlikely to yield sufficient benefit to allow their child to *really* engage in the hearing world while depriving him or her from the legal beneficial status of profound deafness.

CI was also stipulated to cloud identity and cultural belonging: parents feared that implanted children would still find it difficult to socialize in the hearing world while also being deprived from Deaf culture since Deaf adults resent implants. Opponents of cochlear implants suggested that the implanted child would be socialized outside of the Deaf community and would therefore not obtain a Deaf identity. Yet, as is the case with the hard of hearing, implanted children are unlikely to succeed in the hearing world therefore inducing an "injured" self-concept (Myklebust 1960). To date there is no hard data supporting this view however, even though the deduction from the hard of hearing case seems plausible in itself. Nonetheless the argument is still encountered widely: in a recent Gallaudet University publication, psychologist Sussman claims that he is beginning to work with deaf people with implants who are struggling with identity issues and fear rejection by the deaf community (Johnson 2000).

As we illustrated, one control parent was especially outspoken about the desirability of identity-clarity (CO1). One may wonder whom this parent is addressing. Is it "confusing" to her as a parent, to her child or to the world at large? If the latter would be the case, she could simply be referring to the practical fact that the deaf and hard-of-hearing scarcely mingle in real life. If the former is the case, it is less obvious why it is considered of so much importance to categorize a child in either the "deaf", "hard-of-hearing" or "hearing" category. It may well reflect the attractiveness of a simple model to approach one's handicapped child. Specific scripts can be attributed to each of the above mentioned "identities", scripts that parents can follow and that will certainly instill more emotional stability compared to a situation where these scripts are released, meaning that scripts are assigned on an individual basis and may hence contain elements of all three "identities" while the precise "mix" may also change over time. Indeed one case suggested that some parents might not choose for an implant since it implies a disruption of the existing situation and since it demands renewed energy to be invested (C10ab).

By addressing the "benefits" of being deaf, parents acknowledge the tension that exists between denying handicap and giving into handicap fully, which was a recurrent theme in the previous chapters. As long as no truly effective treatment is available for pre-lingual profound deafness, all deaf children will likely benefit from *some* social consideration for their position. Finding a balance between eliminating disability cosmetically and visualizing the handicap is a common theme in disability studies. Dutch author Spaink has elaborated on this topic extensively (Spaink 1993). While externalizing the disability purposely has distinct liabilities, namely that it instantly sets

one aside from the normal and induces a disability discourse, it has advantages as well. These advantages are primarily explained by the indisputable fact that a disabled person is distinctively *different* and benefits from consideration that also comes along with being recognized as disabled. As soon as a physically disabled person abandons his or her wheelchair, the helping hand - however stigmatizing it may be - to get into a bus or train is withdrawn.

Cases shared some of the worries expressed by control parents. In particular they also worried about possible psycho-emotional liabilities and physical dependency. Yet some cases refuted the assumed benefit of "identity clarity", claiming that an exclusively signing Deaf person would find it much harder to engage in hearing society. The assumption that cochlear implantation sentenced children to a cultural "no-man's-land" was also refuted, due to the injustice of rejecting children based on decisions taken by their parents. Some parents even spoke of an exalted bicultural model. Indeed, it appears as though the potential of cochlear implants to yield a *crossover identity* (Rattansi 1990; Rattansi 1995) or *dual identity* (Weinberg 1986) is quite real. Weinberg found that deaf individuals with such a dual identity were the most likely to pursue social mobility (Weinberg 1986; Paul 1993).

Even though we separated construct and content validity, our material shows that the two are not separate concepts entirely, at least if pragmatic rather than ideological reasoning is dominant – implying the exclusion of ideological DC-ID arguments. None of our controls seemed to *really* underscore a foundational identity discourse yet they did often express both aspects related to construct as well as content even though the first dominated. This is shown most clearly by the fact that all controls would choose for an operation in the case of the "perfect implant". It seemed that a lack of faith in the efficacy of cochlear implantation to *truly* better the child's spoken language skills was primary. Primarily as a result of this, parents reasoned amongst content lines, such as the argument that the deaf status offers distinct advantages. It seems likely that *because* parents perceive that the best an implant can realize is a slight improvement in spoken language skills, their child will explicitly remain seriously disabled - so much so that the alternative scenario of Deaf culture submersion is still perceived as preferable.

THE IMPLANT SURGERY AND REVALIDATION PERIOD

Introduction

Cochlear implantation is rather routine surgery for experienced ear surgeons the approach is for the most part identical to retro-auricular middle ear surgery The middle ear is exposed through a retro-auricular skin incision and micro-drilling of the underlying extra-cranial temporal bone When the middle ear has been adequately exposed through a so-called posterior tympanotomy, the specific chapter of the operation is reached this consists of creating access to the inner ear through a cochleostomy and insertion of the wire-electrode Next an extra-cranial pocket, the size of the implant device, is drilled in the temporal bone and the implant is fixed to the bone Finally the skin is closed, elastic bandage applied around the head and the operation terminated The surgical implant procedure is performed under general anesthesia and takes about 2-3 hours on average At the Nijmegen University Hospital, children are admitted to the otolaryngological pediatric ward one day before the operation Typically children are released from the hospital on the second day after the operation The pediatric ward is equipped to allow parents to stay overnight with their child Parents are allowed to accompany their child into the operating theater until he or she is under general anesthesia Post-operative controls monitor wound-healing primarily After satisfactory local healing has been achieved, no further medical controls are scheduled The revalidation procedure initiates a couple of weeks after surgery and usually takes place at IvD Initially several sessions are required to make a child familiar with the device and to find the most appropriate "coding strategy" for the speech processor Though standardized strategies are applied, this process is ultimately very much individual Once this has been achieved, the technical component of the procedure is completed, even though regular controls are scheduled Initially the implant team coordinates speech therapy Yet, after some time this task is delegated to the child's home area In principle, speech therapy is no different than in the case of a non-implanted deaf child Through several methods the child is trained to decipher sounds and use sound cues in combination with lip-reading to capture expressions in spoken language In addition, the child is taught the skills to speak and to produce intelligible speech Ultimately, the intensity of the revalidation process is dependent on the available resources in the child's home environment In this section we will describe how parents experienced this period how they experienced the surgical phase of the process, how they prepared their child, how their child responded to the device and the new input it provided, how the lengthy revalidation period was experienced and how their child handled this

Experiencing the surgical implant procedure

It became very clear that implant teams made an explicit effort to prepare both parents as well as their deaf child for the impending surgery. Besides informing parents, implant teams also prepared the implant candidate for the impending procedure. Cartoon booklets were offered in which the events were depicted.

M He was informed very well They had booklets for kids, which they could draw in
I Also about the operation?
M Yes, and the things that would happen after that (C12ab)

Many parents actively informed their child of the awaiting operation In particular older children were involved in the process (C1a, C2b, C3b)

I Did you try to discuss it with him?
M Yes, and he fully agreed Sure you cannot put too much value on that, but we did involve him with the aid of books, at child-level He understood it very well and agreed (C12b)

I Did you involve her in the process?
M Yes, we did We had this little book to show her what was going to happen and that kind of stuff (C15)

I He was six years old Did you explain what was going to happen?
M Yes, with a toy bear and the device
I A "toy bear" and the device?
M Yes, we shaved some hair off [the head of the toy bear] and explained everything (C16b)

Some parents also informed their child about the downsides of the operation

M We were frank with him We told him that it would hurt after the operation And that he was likely to feel sick, perhaps nauseous So we were realistic We did not down play it Just the way it is (C3b)

Regarding the expectations of the operation, most parents were rather modest when informing their child

M We always told her exactly what was going to happen
I What did you tell her?
M We told her what was going to happen and that afterward she could perhaps hear a little (C10ab)

I What did you tell him?

M: That we were going to try to let him hear a little again and that it would take a lot of nasty things. Not like he was going to hear like he did before, but maybe a little: "maybe you'll hear a horn; maybe even my voice or you own voice".
I: Did you feel that he understood it?
M: He sure did, very much so. Not that he could make a weighted decision, but he did understand. (C12ab)

I: What did you tell her?
M: That she would be operated and that afterwards she could maybe perceive some sound or hear.
F: More so sound, that she could perceive sound.
M: Yes. (C15)

Notwithstanding the relatively mild nature of cochlear implant surgery and the low risk of complications, some parents feared the operation. Yet this fear seemed to be rather generic and not aimed at the specific procedure.

M: I think we had more problems with the operation than she did, she was well prepared.
I: What kind of problems?
M: Well, just like any other operation. The concern like, how will she get through it? But we would have experienced the same with any other operation. (C10ab)

For others it appeared that discomfort over the operation was a *proxy* for the general decision-making difficulties that we discussed before. Cochlear implantation is elective surgery that is contested by some. Parents decide for it, yet it is unlikely that this choice is ever non-ambiguous. The operation itself may hence become the focal point of this ambiguity.

F: I think it is the operation [that explains why some parents don't choose for an implant-ccw]. They say that it is just a routine middle ear operation, but you dó choose to expose your child to it. It is not necessary isn't it. One can get by without an implant. (C15)

The surgical implant procedure itself was generally experienced as a windfall. Children suffered minimally and typically recovered within a day or so.

F: Wednesday [day after implantation-ccw], when her grandparents called...she was already biking around.[...] They had these tricycles on the ward and was riding on one the entire day. [...] Head wrapped in bandage and all those people looking. (C2b)

Only one parent mentioned that their child had been severely ill in the post-operative period (C3b).

Experiencing the revalidation process

The first activation of the implant device generally did not induce much stress in the deaf child Only one child experienced difficulty, while two others needed time to adjust to the new situation

M When he was hooked up for the first time, he reacted violently to the sound Tears came in his eyes He became warm, red and sweaty He did not enjoy it when it was loud He did not like it in the morning, as he would become all red and sweaty We would put it at 0 5, later to 1 5, very carefully we increased the power I think it took a full year, perhaps even longer, before he was completely adjusted to it (C12ab)

F It was not until the second week when she suddenly wore it during an entire day (C2b)

F The first few months that he had the implant he did not want it, he did not like it (C8b)

If parents encountered resistance in their child, this seemed to make them question their decision This suggests that parents truly fear that their child will not welcome the decision they took

M When they were adjusting the speech processor during her revalidation as soon as we left the room she would remove it [CI] She did not want it That resulted in a lot of stress At a certain moment I said to myself 'I wish that I had never done it' (C2b)

As a consequence many demanded little from their child, particularly during the first months after implantation (C8b)

F We agreed that in the beginning we would do things slowly [ ] But once he gets used to it and uses it all day - that is fine (C14b)

M They [implant team] said that we had to exercise this and that I feel that you risk that your child will come to feel like 'I do not want that' (C15)

M The first 6 months he hardly used it We started with 30 minutes, an hour (C16b)

Three cases, all parents of a relatively young child, explicitly avoided any "top-down" approach and allowed their child to use the implant to his or her own discretion for a prolonged period of time

I So how did you deal with it at home, did you offer it to her all the time?
F Not if she did not want it [ ]
M No, we did not do that
F No, otherwise she would turn against it We just let her decide If she said 'no' we allowed her to put it away Just an hour and then we would put it away (C2b)

F: We have to keep asking: "will you wear it for a little while, because we are going biking or whatever" (C13)
M: If he goes to bed and wants me to read for him he can choose to wear the implant, I will read to him then, or take it off and let me sign to him That is up to him (C14b)

We also encountered active attempts to give the child control over the implant. Parents aimed to give their child power over the implant, not only in terms of when to use it but also in terms of maintenance.

M: We allow him to open it himself to change the batteries.
F: It is his so I think you should give him the opportunity to deal with it. Give him power over it (C14b)

Parents apparently felt that it does not make sense to demand that the implant is worn all day long. If the implant is a "tool", as some suggested, like all tools it must have its specific field of application. Making a child wear the implant all day would deny this aspect and would suggest that the implant is more than a tool. Some parents clearly wanted to avoid this, apparently in anticipation of limited results and the odds of rejection if expectations were presented to high.

F: It should not become an obsession to her like: she must have it, must have it because it is her savior to the world. (C13)

In spite of cochlear implantation, most all parents also insisted on using Sign language in the home environment and many consciously kept their child at a signing deaf school for quite some time. Yet ultimately such a crossbreed strategy is likely to go wrong. Cochlear implantation requires at least *some* oral training to be of any significant effect. If one cannot provide oral training at all because of the aforementioned motives, implantation is likely to be little more than a symbolic act. Parents who challenged their child very little in oral terms, sometimes seemed to refute this hypothesis assuming that children would start using speech "naturally".

I. What do you think would be the result if you did not stimulate her to use speech at all and had just followed her in her natural tendencies
M: I think it would be a mix, Sign and speech I think. Yes, both I think. (C2b)

It thus seemed that many parents had silent concerns over aversion, which led them to empower their child when it came to handling the implant device. Implanting a child at a young age was considered favorable because it was considered less likely to yield aversion.

M: If you reason logical, a young child just finds everything rather normal. At a certain moment he found it rather normal that he was wearing hearing aids. He finds it rather normal to take a pill everyday. He never asks why We adults create the problems, not the

child. He wears the implant every day. It does not bother him. He wears it. He has just accepted it. I have heard from a mother who implanted her child at age 8, and she told me her daughter uses it at school only. As soon as she comes home, she removes it. Our son does not make that distinction; he just wears it all day I think it is because of his age. It is just like putting on shoes, putting on the implant. (C14b)

While some considered age of implantation of importance, others felt that the child's social environment was essential in determining how he or she would come to deal with the implant. Given the antagonism against implants in deaf ecology, some parents feared that this could negatively influence their child's attitude towards the implant. Because of this one parents felt "forced" to withdraw her child from the signing deaf environment.

M: He is deaf and is allowed to be. But because the Deaf world is so negative about it [CI], we are forced to withdraw him from that world. To prevent negative emotions, psychologically. [...] This Santa Claus [for deaf children-ccw] party is coming up soon. We would love him to attend, but if I notice that they look at him negatively like "that kid with an implant" you would almost want to hide it or remove it just for that occasion (C14b)

The negative attitude observed in deaf ecology did not only pertain to the device itself, but the gain in hearing that it produces as well. Deaf culture has been known to make a hierarchical distinction based on the degree of hearing loss (Wrigley 1996; Bertling 1998). Some parents perceive this as a potential problem.

M: We chose for cochlear implantation consciously, but he is expelled from that world [Deaf world]. I know a story from a deaf woman who is married to a hard of hearing husband. The husband was not accepted by the Deaf world, because he still had some hearing left. I cannot understand that. (C14b)

The revalidation process was considered strenuous by some parents. Especially parents residing in the northern provinces complained about the long traveling time to the revalidation center (about 2-3 hours by car) and the long stay away from home.

M: I think it demands a lot mentally.
F: If I look back at it, I realize that it did demand a lot. Mostly from our child. You have to travel for so long, so I feel like it is a lot for such a child. (C15)

M: I always tell prospective parents that they must be comfortable with themselves before they start with it [CI]. Because the whole thing can really disrupt one's life if you are not in top-shape at the time when you start with it.
F: Only consider the logistics. We had to travel from Friesland to Den Bosch. We were in the south almost every week in the beginning. You need very good planning for the family. We have three other children you know. (C7a)

In addition to these strictly implant related efforts, parents of older children were regularly approached by the implant team to brief aspirant implantees as well as to engage in issues such as media coverage.

> *M: Well, you start with it and before you know you are on a roller coaster. It is sort of a circuit. Though it has become less, other activities are on a rise.*
> *I: Can you explain?*
> *M: Well, the whole operation and such is behind us now. It is just a matter of maintaining the implant. But now there are other things, like [...] other parents who call [for information].*
> *F: They want to know what we think about CI. It just keeps you involved. (C7a)*

Finally we mention that some parents of the older children said that they longed for extended guidance by the implant team, which typically retreated one or two years after implantation (C4ab).

Specific issues, cases and controls

Kelsay reports that one in five parents worry about resistance in wearing the cochlear implant device prior to implantation (Kelsay 1996). From this one could argue that fear of rejection is prevalent amongst parent of recently implanted children mostly. Indeed, the majority of parents responding to this issue had a deaf child of six years or under.

Discussion

Parents were often very careful to avoid aversion when the revalidation process commenced. This was evident through the fact that they often demanded very little from their child at that time. The child was allowed to decide if and when the device was used or not. It was also evident through the way parents provided their child responsibility over maintenance of the device. Fear of aversion seemed to be an important issue for parents of the more recently implanted children. There may be several explanations for this. One explanation is rather similar to what we discussed on the anxiety surrounding the operative procedure. Like this procedure, the initial fitting of the implant may be seen as a *focal point* of the ambiguity that surrounds the decision to implant. If this process fails, the haunting uncertainty that preceded the implant procedure comes to the forefront rather brutally. Yet parents also appeared to connect the resistance of the adult Deaf population to the mindset of their young child. Granting a very young child autonomy over the implant device seems to be an anticipation that their child too could hold or develop a deep aversion towards the device. This latter suggestion could imply that not so much the intrinsic risk of failure, but rather the affinity with the story of Deaf adults determined why these parents were worried over aversion more so than parents of older

children: it could be that, as a result of geographical and time factors, these parents are more aware of the resistance of the adult Deaf population vis-à-vis cochlear implantation.

Several parents experienced the operative procedure as strenuous. On the one hand it appeared that this fear was rather generic in character, hence unrelated to the specific context of cochlear implantation. Indeed several studies have found parental distress around elective surgery in general. Utens and others for example, report elevated levels of anxiety in parents of children undergoing elective cardiac surgery or catheter intervention (Utens 2000). These authors found no difference in anxiety between the surgery and catheter intervention group. Another study reports that over 40% of parents of children undergoing elective surgery experience significant anxiety (Shirley 1998). Both studies found that mothers were generally more anxious than fathers. The fact that children were generally young at the age of surgery and that cochlear implantation was their first surgical procedure may add to this (Litman 1996).

COCHLEAR IMPLANT RESULTS

Introduction

As we have mentioned before, critics have pointed out that implant results are rather disappointing. On the other hand, a few questionnaire-driven studies have shown the opposite (Osberger 1997; Christiansen in press). Yet, "outcome" is not a priori investigated best through questionnaires nor is it best to initiate such studies through an implant team. As we have illustrated, implant teams made a strong effort to temper parents' expectations prior to implantation. Additionally, parents are generally aware of the controversy surrounding cochlear implants. Both these factors may influence how parents judge implant results in a questionnaire format. An *explorative* interview setting on the other hand allows increased scrutiny. In this section we will describe how parents responded to our inquiry on post-implantation results. We aim to describe these results as well as clarify how parents perceived of them. Asking parents to respond on implant results requires sensitivity to time factors. Cochlear implant results are known to be gradual, typically covering many months or even years. To compensate for this we will separate "early" and "late" utterances. Early utterances focus on the narratives of cases implanted less than 18 months before the interview (C2b, C8b, C13, C14b, C16b). Late utterances focus on the narratives of cases implanted at least 18 months prior to the interview.

Early implant results

Progress after cochlear implantation is a process that takes several months or years and is likely dependent on the child's pre-implant language memory and the post-implant level of spoken language exposure. One child did not have any benefit at all (C3b). The official explanation was dyspraxia. Interviews with parents of recently implanted children indicated that the process was slow indeed. Initially no tangible progress was noted at all.

> *I: So how was the first year?*
> *M: We hardly noticed anything at all. Everyone was having doubts (C13)*

> *M In the beginning he did nothing at all. He was still very much deaf. He did not respond to sound He did not respond to our voice. He did not do much with it at all, and he did not use his voice. (C14b)*

Yet after some time, most parents did observe change. Generally the initial change was rather subtle and may even seem frivolous to an outsider. One of these changes was behavioral in nature (C8b). Perhaps alluding to the previously mentioned benefit of

increased environmental awareness and sense of connectedness, parents said that their child became less introverted and more open to the world after implantation

M She became more cheerful and kind, more accessible too (C13)

M He has become more involved in our family life [since implantation-ccw] If the battery is dead he is much more in his own little world (C14b)

Some parents reasoned that the surplus attention that a child enjoys as the result of the implant co-explains these observations

F The world is more fun to her now with sound and she enjoys making contact with sound
M To "score" also, I think Because she is Look she always had good contact with us and her sisters But with other family members, that was much less the case uncles and aunts, nieces and nephews Now they suddenly hear her [using sound] and seek out as a result because they see possibilities for engagement She enjoys that a lot (C13)

Concrete yet rudimentary environmental sound awareness was also reported (C16b, C8b). Children slowly became aware of the sensation and meaning of environmental sounds, which sometimes triggered an enterprising attitude

M At a certain moment when I would use the vacuum cleaner, I would say to him "look this is a vacuum cleaner" Slowly I noticed how he would turn his face more often At a certain moment he would start to beat on the table, with plates, knives, cups and would be like "hey, what do I hear? I hear it!" He would walk over to the radio and turn it up, like 'do I hear it?" Then he would take off his implant and do it over again 'Now I do not hear it" So you could notice it after a while
F He would make a game of it
M It became clear to him that he noticed something he never did before That was real fun to experience (C14b)

M He is starting to discriminate between a car and a truck or as he sees it "a big car" and 'a small car" If he hears the lawnmower he will ask what it is If there are a lot of people around, he will ask 'what is all that sound?" So we explain that it is voices (C16b)

Parents considered this newly found awareness as an enrichment, perhaps because of the expansion of the "sensorial horizon" that it entails

M He never used to play with toy cars, they did not appeal to him He only played with animals, because he could see them move But since he has his implant and hears cars he is playing with toy cars He will be playing with them, making sounds like "brrrrmmmm" He never did that before So that makes me think that is an enrichment of his life or not Those people [critics] should see that should see how fun he finds it to be involved with sound (C14b)

Parents actively stimulated this learning process, encouraged their child in his or her voyage

> *F Once we noticed it, we started to alert him at sounds more frequently If a plane would pass over we would be like "listen, a plane!"*
> *M "Do you hear?*
> *F He would start searching, would notice the plane and linked it to what he heard After a while when a plane passed over, he would point and sign plane" (C14b)*

A related and much valued benefit was that, as the result of sound awareness, children could be called upon through the use of voice (C8b)

> *M You can call him with your voice he will turn his head promptly (C16b)*

Yet sound awareness was not the only result parents observed in the early post-implant phase Many parents also reported that their child became increasingly "voice-active" This must not be mistaken with the production of language per se Even children who were completely silent, started making sound spontaneously (C16b)

> *M He did not use his voice at all At a certain moment he would pretend to be asleep and when I came to get him he cried 'whaaah" In the beginning it was just one sound (C14b)*

Again, parents often responded blissful

> *I He never used his voice before?*
> *M Never [ ] So after a while he did start using his voice, like Aaah, Aaach two sounds he used We jumped in the air like 'he is making sound!' That was something! It is so normal now, he makes sound all day long [ ] So he started to use his voice more and more frequently, with new things all the time (C14b)*

Sometimes it seemed that environmental sound awareness and the use of voice were synergistic developments, since children tried to mimic the sounds they registered

> *M Things that he hears, like birds He will be listening carefully and succeeds in naming what he hears like the microwave he alarms us when the microwave rings*
> *F He tries to imitate is, with a very high pitch voice like 'peep, peep peep" (C14b)*

Most children eventually reached beyond environmental sound awareness and rudimentary use of voice With the exception of the above-mentioned failure, all children eventually produced words or even small sentences, though the latter occurred in one case only (C2b)

> *M She speaks in three word sentences Short sentences (C2b)*

Additionally, the intelligibility of speech utterances increased Even recently implanted children made headway in this respect

> *F After one year she is starting to move forward and we notice that When she signs she supports her sign with sounds She is producing more sound now and is intelligible She can say quite a few words that we can understand (C13)*

Children who had previously been communicating exclusively through sign, became more oriented on speech and lip-reading

> *I How is your communication with her?*
> *M Good She really speaks to us*
> *F She navigates on her hearing almost exclusively*
> *M She really looks at your lips now If I sign and speak simultaneously she will no longer focus on my hands but on my lips (C2b)*

Some parents recounted that, in spite of advances in voice-activity, their child sometimes overestimated his or her speech potential In particular when exited, implanted children were inclined to speak rapidly which compromised intelligibility

> *M Of course she can tell you long stories, but you won't understand much (C2b)*

Some parents realized that an environment in which Sign language dominated was not the most favorable to attain spoken language skills Indeed, Daya and colleagues report better speech perception skills in implanted children who are mainstreamed (Daya 2000) Parents experienced the advantage of implanted children at a school for the hard of hearing or a mainstream setting firsthand

> *F They [implanted children at a school for the hard of hearing-ccw] are doing rather well We have firsthand experience with this girl with an implant at such a school*
> *M She is doing very well*
> *F She speaks very well So the comparison with children enrolled at [sign-oriented-ccw] deaf schools made us change our minds We will transfer him to a school for the hard of hearing, because the results are better there (C14b)*

This prompted some parents to consider a transfer away from a signing school for the deaf Daya reports that 70% of parents of pre-school implanted children consider such a choice (Daya 2000)

> *F We visited a school for the hard of hearing two weeks ago and it opened up our eyes They were really interested in how to teach him speech We are forced to take him away from Deaf culture while it is not our intention [ ] Well, we feel like now he has this expensive piece of equipment, we'll have to do our best to get the most out of it In that context we feel that if he stays at that school [sign-oriented deaf school-ccw] maybe he will speak eventually but it will take years compared to a school for the hard of hearing*

where they speak to him constantly Supported with sign of course. So that is why we have chosen for that school for the hard of hearing. [...] (C14b)

Some parents even perceived such a transfer as the actual start of the revalidation process.

F: He will transfer to the school for the hard of hearing in august. So the first six months with the implant our attitude was: Now he has the implant, he wears it and we will not demand too much, we'll keep him at deaf school for half a year so he can continue with Sign language and develop further in it - we like that. In august he will go to the school for the hard of hearing and at that point we will start the actual route that we want. (C14b)

Another reason to transfer an implanted child was that, according to some parents, signing schools did not know how to deal with these children.

F: They just did not know what to do with implanted children. (C14b)

Thus, cochlear implantation did seem to promote or accelerate some processes, such as school transfers and changes in language environment. Still, most of these children were enrolled at deaf school and additionally many parents persisted in the psycho-emotional discourse that we delineated in the previous chapters.

In general parents were somewhat disappointed by the early results or at least were not bluntly positive about it. The disappointment was largest during the first few months after the procedure, a finding that has also been reported by Christiansen (in press).

M: In the beginning we really felt like "Oh, this is never going to work out".
I: It was disappointing?
M: And if it was! I know I should not say this, but...(C2b)

Thus, some parents had apparently expected faster and better results, in spite of the unpretentious information provided by the implant team. One parent of a child that was implanted 6 months prior to the interview commented:

M: They told us that it is going to take a while, but we did expect that he would respond instantly, right after his implant was fitted. Yet he did not. [...]
F: Even though the information was clear, that it could years before the results would be clear. When he just got his processor you do hope that he responds.
M: Yes, that was a disappointment. (C8b)

Late implant results

Cochlear implant results improved with time. Of the 11 children with at least 18 months of implant experience, all but one (C3b, non-user) attained the level depicted at the conclusion of the previous section. Five parents, all parents of children in subgroup A (≥ 10 years, deaf after age of 2), reported "excellent" spoken language skills (C1a, C4ab, C5a, C9a, C12ab). Most of these successful cases previously attended the IvD School for the deaf or a school for the hard of hearing (except C5a and C12ab). All were mainstreamed at the time of the interview.

> *M: Once she had the implant, she started to speak more. When she came home from revalidation she would tell us everything, she would make sentences. (C1a)*

Similarly to what has been suggested by some, the use of Sign language decreased as these children made headway in speech.

> *M: My parents are here rather often, because my husband and I both work they look after the kids. They are signing less and less, close to nothing at this point. Without it being a problem, if that was the case they would have continued signing. It just faded away because with the implant he is doing so well that the need for Sign has diminished. Not in the Deaf world, but at home. (C12ab)*

Four parents reported "marginal" spoken language skills (C6, C7a, C10ab, C15) and one "poor" skills (C11). Parents reporting marginal or poor skills all attended a Sign-oriented school for the deaf. Even after years of implant use, speech was still hard to comprehend for the untrained other in some of these cases.

> *F: Her speech is not optimal of course. For many peers it is strange, scary even.*
> *I: Is it comprehensible for others if they try?*
> *M: Yes*
> *F: I think that is too optimistic.*
> *M: No, I think people can [if they try-ccw]. Particularly if she pays attention and uses short sentences only. That is her problem at this moment. She tries too much to use full sentences. If she uses short sentences and does it with force, she can be understood. (C7a)*

Nonetheless, the majority of experienced implanted children eventually at least attained a level of speech intelligibility that allowed them to communicate orally in the family environment and engage in hearing society. This was true for the less successful cases as well.

> *F: She does groceries by herself. She does just fine. If she needs something, she will go and get it herself on her bike. (C7a)*

> *M: She always speaks. She uses Sign simultaneously sometimes but with us she hardly does. I can understand her just fine. (C6)*

Having command over intelligible speech and increased communicative skills apparently improved the child's ability to interact with hearing peers and engage in hearing society in ways unthinkable before

> *M If we go camping she knows nobody but before we know it, faster than her [hearing] sister, she makes contact with other children She is very open, just walks up to everybody and starts conversation and play (C7a)*

> *F Our youngest [hearing] child is afraid to even go to soccer while she [deaf child] heads off with her folkdance club to Germany for three days she feels fine (C9a)*

> *M She has to sell children-stamps for school That is not a problem at all, she just walks over to the neighbors and sells them (C10ab)*

Though the social situation was often not ideal, it did improve after cochlear implantation.

> *F Of course it still happens Children at her school will talk to her while not facing her or at a distance It still happens regularly It even happens in the family [ ] But is has improved [ ] She has become more assertive She manifests herself She holds her own brilliantly (C4ab)*

Cochlear implantation never resulted in a normal "hearing child" in the sense that it always remained rather obvious that an implanted child suffered from a severe hearing disability

> *F She is deaf but she is not That is because of the implant Sometimes she is like hard of hearing, when she does not wear it she is deaf (C4ab)*

Nonetheless, most parents valued the progress made as a result Parents seemed to feel that normalizing was not required to speak of "success".

> *M She still talks funny, but in general she can manage with just about everyone and succeeds in getting the message across Not perfectly, but effectively (C9a)*

Ultimately is seems that implant success is to be determined by the child him or herself Some of the older children were content with cochlear implantation.

> *M To this very day he never regretted it, in spite of the operation, the revalidation He has always been content with it (C12ab)*

> *F If I ask her if she can do without the implant she is very clear "No, I really can't" (C4ab)*

Non-use may be the most evident sign of failure. Archbold reports that 89% of her sample used the implant full-time three years after surgery, non-users were not registered (Archbold 1998). Some children wore their implants throughout the day.

> *F: She never takes it off*
> *M: Just the whole day, she wears it the whole day. [...] Only during gym or when she goes swimming, she takes it of. (C15)*

Parents of more experienced children were much less lenient towards the deaf child's autonomy to use – or better, *not* to use - the implant to his or her own discrimination. Wearing the implant was depicted as a responsibility the child *had* to take.

> *M: We tell her: "you have to choose: do you want to follow what we say or not?" If you want to, you must wear it.*
> *F: We put her before that choice: "you either wear it and understand us or you do not."*
> *M. But we will not repeat ourselves over and over. (C4ab)*

> *I: When does he not use it?*
> *F: In the shower and in bed.*
> *M. As soon as he goes to school he wears it. That is our predetermined rule. (C5a)*

> *M: I do not find it proper towards hearing people [not using the implant-ccw]. Because they have to do their best to understand you. [...] I think she has to use her potential. (C10ab)*

However, not all children in our sample used their implant this frequently. Some only used it during school hours. From this it appears that some children are inclined to use the implant *semi-formally* so to say, in situations where they are explicitly expected to achieve communicatively.

> *I: How often does she use the device?*
> *M: Mostly at school. And at speech training, that works really well. (C10ab)*

In support of this finding is that some children consequently did not use the implant at home, during weekends or vacations (C4ab).

Some children experienced the cochlear implant as a hassle. In particular the fact that the equipment consists of a portable processor and a behind-the-ear device was not appreciated. The awkwardness of the processor was unwanted since it inhibited freedom of movement. This limiting aspect of the implant device was commonly illustrated by referring to "warm summer days", which may be said to semiotically represent freedom and play (Hays 1996).

M: He wants to become an inventor and wants to design an implant that fits behind or preferably in the ear. He just feels it is rubbish, a hassle, particularly when the weather is warm and he wants to wear shorts. (C12ab)

M: It [speech processor] is annoying.
F: She wears it on her belt...and it will often flip over. (C15)

M: The only time he does not want to wear it is when the weather is very warm. Because it will become muggy in his ear (C3b)

Moreover, the visibility of the device was not appreciated. As we argued before, the speech processor externalizes the disability and hence may become a focus of stigma. Apparently some older children did not appreciate this.

I: Are there things that she does not like about it?
M: The speech processor, the processor. She does not fancy that.
F. The processor makes everything so visible. (C15)

Some sounds were actually experienced as irritating. This appeared especially true for loud high-frequency sounds.

M: If our son screams, she finds that an irritating sound. [...] She feels the same about my husband whistling. She will comment on that, like "I do not like that". (C15)

F: She takes it off in the car because the sound of the engine is irritating she says. (C2b – inexperienced user)

Two parents of inexperienced (< 18 month use) children spoke of a more encompassing annoyance over sound.

M: He says that he does not find some sounds very beautiful but rather annoying. So I told him that we also do not like some sounds, like that of a vacuum cleaner. So I will play music, but it is all the same to him He can distinguish if we are talking or if he hears a vacuum cleaner, but he dislikes both. (C16b)

M. The noise, it makes her tired. (C13)

These children seemed to develop a more fundamental ambivalent attitude towards the implant. This was especially true for one case.

I: Does she express how she feels about it?
M: About CI? Well, sometimes it annoys her; she will say that she does not like it, that it bothers her. But if she is in a good mood, she's positive. (C13)

Yet other parents reported no such hassles.

M: No, it does not bother her. It is just a part of her. If it is not on right, she will correct it. If the spool comes off, "hup" she puts it back and continues running (C2b – inexperienced user)

Even some of the younger implanted children seemed to develop a "relationship" with their implant rather soon.

F: He asks for it himself Once the batteries are empty, he will come to you like "finished". He notices and wants a new one [battery] promptly He does not remove it until bedtime. In the beginning when the spool would come off, he would place it back right away. He would notice the difference He just enjoys it. (C14b)

Judging implant results

Parents indirectly derived implant benefit from the child's response when the device failed. This occurred most often when the batteries ran out. More specifically, without the implant speech quality rapidly declined.

I Do you notice a difference when she is not using it?
M: If she does not use it for some time, you notice that her speech becomes messy I think it aids her in her speech. (C10ab)

M: You can really notice when it is broken. She falls way back. She becomes introverted, cries a lot. This way we can notice that she really does benefit from her implant. [...] She becomes silent. (C2b)

The ability to engage in communication also decreased without the implant.

M: He feels very frustrated if he does not understand someone. With the implant that happens less than without it. He reaches a higher level of communication with people than before. His speech improved and with it the communication with hearing people was strengthened (C12ab)

Some parents suggested that the implanted child felt more at ease wearing the implant.

M: He feels safer. You notice that at night If he is scared he will ask for his implant. So he can hear everybody, as he expresses it. (C12ab)

Yet parents also narrated about results more directly. As we have shown in the previous section, initial cochlear implant results were rather modest, limited to some environmental sound awareness and increase in verbal utterances. After time, many parents reported definite development of spoken language skills that allowed their child to engage in hearing society. Parents of children from subgroup-A were mostly highly content with the results (C4ab; C10ab).

F: I mean, if I would have to sell our house for it I would. I would take a second mortgage. (C9a)

I: If you look back at the past 7 years with a cochlear implant, what would be your comment?
M: Brilliant!
I: How is that'?
M: Just, the ease in learning language and communication. (C1a)

M: We are very proud of her, how well everything is going. We are very pleased. (C10ab)

The normalizing desire that we refuted in previous chapters, sometimes did surface in parents discourse after cochlear implantation: parents valued cochlear implantation because it had near-normalized their child's situation.

F: We are so gigantically satisfied with it. We say: things are almost normal. Sure, what is normal? Well, a little like things ought to be. You just have three kids and you take them to school. They come home with friends, so everything just goes its normal way. It is almost normal. The past six years [since cochlear implantation-ccw] have been close to normal. (C9a)

Even though these parents were content with implant results, they refrained to generalize their experiences.

M: I cannot make a statement about that, about if one ought to implant a deaf child or not. Just like what is the best school. I just know that if I look at him [deaf son], cochlear implantation has worked out well. He can do a lot with it. (C12ab)

M: You look for a road that is best for her; she still has her entire future ahead of her. But that is not to say that it [CI] is best for everyone. (C1a)

Yet not all parents of experienced children were outspokenly positive. Apparently even parents of the most successful implanted children were still uncertain about what the future would bring. Thus apparently results were not so grand that it eliminated the reservation about the future that we discussed in chapter five. Hence, parents recognized the possibility of failure in the future.

F: If I look back I can say wholeheartedly that the past six years [since implantation-ccw] have been very good. But that does not say anything about the next six years. In this sense it remains something we will just have to wait and see. (C9a)

For others reservations were more substantial. As time progressed and results became more evident it appeared that some parents had hoped more, even though one would not expect such expectations based on the restraining attitude of implant teams. Christiansen reports that parents hope for somewhat better development in terms of spoken language

(Christiansen in press). This was true in this study as well. Even some parents of the most successful implanted children carefully acknowledged that they had wished more in terms of spoken language proficiency.

> *F: She is still very young, so we still have time Yes, we did hope that we would have been further by now, but all right. We have gotten used to it and think: we just have to be patient. (C9a)*

Additionally, some parents had hoped that spoken language developed at such a level that mainstreaming would have become an option.

> *M: When we started with cochlear implantation we hoped that it would yield such results that she could be mainstreamed in the neighborhood. Now we know that that expectation is not realistic, but I did not know then. We hoped that we would succeed. (C7a)*

Apparently, silent "hopes" as opposed to concrete "expectations" played a much more central role and determined how parents ultimately judged implant results. Hence, the modest information provided by implant teams did influence expectation but did not appear to prevent parents to hope for more.

> *F: They were careful. Very careful. I will never be able to say that Nijmegen was not careful. They never said like "your child will become hearing". Still I find the difference large, between what I had hoped for and what materialized. (C7a)*

Notwithstanding marginal results in some cases, some parents apparently did not expect or hope for much more as they expressed contentment with these results.

> *M: We are very pleased.*
> *F: We are pleased without any reservations. We expected the implant to improve her response to voice and environmental sounds in the street. If we look at what she has reached now, we can only say: Wow.*
> *M: It exceeds our expectations. (C15)*

For others, sub-optimal results did lead to disappointment. Yet it did not always lead parents to question or regret the decision they had taken.

> *M. Too bad. You know, our expectations were minimal. So we did not experience a backwash or something We never came to question what we had chosen for. (C3b – non-user)*

In particular parents whose child attended one of the signing institutes were ambiguous. These children generally performed relatively low, which magnified the problems encountered - such as large classes, foreign language requirements, the lack of amplification devices, inconsiderate peers and teachers - when contemplating mainstream

education. These parents sometimes persisted in the psycho-emotional discourse that we described in the previous chapter (C6, C7a, C10ab; C12ab).

> *M: For us the most important thing is that she is happy. Of course we stimulate her in a certain direction, but ultimately if she is happy and has nice people around her that is fine. (C10ab)*

Mainstream education was often still considered non-achievable given the liabilities mentioned above. More explicitly than in other cases, these parents often still perceived of the Deaf world as their child's likely future social environment, since the threshold towards the hearing world was considered too high.

> *M. As parents we feel that she will have to walk on her toes too much [in the mainstream-ccw], in spite of her implant [...] Coming from a deaf school being placed in the hearing world, needing a Sign translator, not hearing enough: that is hard She will never be able to follow things. I think it is not easy for such a child. So we will enroll her in deaf high school instead (C6)*

Since some of these children were entering their adolescence, parents feared that *forcing* the child into a mainstream setting would compromise their sense of self-esteem and as such could inhibit them to continue to make educational progress.

> *F. For a child at that age it is easier to develop around people with whom she can communicate well. If you attend mainstream school that becomes a problem. If you need translators and cannot keep track of class instruction. That may cause frustration, like. "I cannot follow class, what am I doing here?" Surely there will be children who will say: "I am going home, this is no use to me". (C6)*

Yet these arguments appeared local in origin, implying that the choice for deaf school was not fundamental. This materialized from the fact that many parents still hoped that their child would *eventually* succeed in finding his or her way to a mainstream educational setting.

> *M Sure we hope that she will attend hearing post-secondary education But you should see it as a hope, a wish perhaps (C6)*

These parents also often persisted in using Sign language as their prime means of communication in the home environment. This appeared to be a rather principal position for some, even though no alternative was available (with the exception of C5a) because of the mediocre skills in spoken language terms (C5a; C11).

> *M: I think that - it may sound strange to you - I think that we are the least involved with speech in our household [of all families with implanted children-ccw]. (C6)*

Disappointing results were mostly explained based on unavoidable inter-individual differences, additional learning handicaps, partial insertion of the electrode and age of onset of deafness (C6). The revalidation environment itself was never raised as a possible confounder of results, with the exception of one parent.

> *M: His [sign-oriented] school never did enough about it [speech training-ccw] and neither did we. I think we allowed it to roll on for too long. We thought it was enough, but we should have communicated more with him and should have started two years earlier (C12ab)*

What was evident about the narratives of parents of experienced children was that many of them were deeply involved in actively planning future educational routes, as we discussed in the previous chapter. These routes often included contemplation or implementation of mainstreaming in high school. It often appeared that parents were not so much involved with the implant itself, but much more so with the time consuming task of creating opportunities in a world that lacks consideration. Parents encountered new and significant obstacles in doing so (C7a; C5a; C12ab).

> *F: These are barriers that you have to take, over and over again. (C4b)*

> *M. You are so dependent on the readiness of schools, of teachers [in the mainstream-ccw]. Because they do need to invest much more than they would with a hearing child. That is really vital. (C9a)*

Even though the implant may yield significant results, results were not sufficient to avoid these rising problems. This may have prompted parents to shift their demands of the implant upward.

> *I. Are you satisfied with the results?*
> *F. I am*
> *M: Yes, but I always want more...it could be more with his speech and language (C5a)*

Other parents perceived of these problems as rather separate from cochlear implants.

> *F: Success is dependent from a lot of factors, not only from the choice for or against a cochlear implant. (C9a)*

Even after cochlear implantation, problems persist which evoked a general dissatisfaction with the global situation.

> *F: As long as uncertainties persist you will remain dissatisfied about how things are going (C5a)*

Parents also spoke of outcome from a more global perspective. Several issues of concern were raised: 1) concern over the equipment and 2) response of deaf peers. When asked if

parents experienced the fact that their child carried around expensive equipment as a burden, some replied confirmatively.

> *M You worry automatically because he has a part in his head Things go well now, but in the beginning he fell a lot and that scares you*
> *F He was very clumsy, he fell over all the time, so that is worrisome I feared that he would have to go back to the hospital (C8b – inexperienced user)*

This was not true for all parents however.

> *I Do you worry about the fact that he carries fl 50 000 on his belt so to say?*
> *M No, we took insurance on it In the beginning I did feel uncomfortable, but I try to make myself more relaxed about it Because he is a kid, so once in a while something will happen with it He has fallen into a pond twice with the processor Luckily things were all right [ ] No, I do not have qualms about it anymore, which is not to say that I have no feelings towards it at all (C12ab)*

> *I Do you feel worried about the equipment?*
> *M In the beginning we did, but not anymore In the beginning we were very careful But now it is just there, it is a part of life (C2b – inexperienced user)*

The fact that the child was fitted with delicate equipment beneath the skin of the head also troubled some parents.

> *M He does have a thing in his head Once he fell really hard with his bike, his skin was bruised That worries you, like "I hope he does not get an infection or something" It is a device after all, so there are risks (C16b – inexperienced user)*

Deaf peers sometimes responded negatively to the implant. One parent whose child attended a signing institute narrated:

> *M Sometimes he is teased because of it He was lucky to have about four implanted children in his class So together you stand strong Still sometimes kids say ridiculous to have such a thing on one's head Just like children with glasses may be teased Sometimes it went even further with deaf children of Deaf parents They would say "if you wear it, you will die" I know one kid did not want to use the implant anymore and he [son] also felt uncomfortable like "Is that true Mom? I do not understand Am I going to die?" Really strange stories (C12ab)*

> *M Those children are tough At a certain moment one kid came up to me with a flippo [a coin-shaped toy – ccw] and held it behind his ear saying, "Look, I am John" [fictitious name of son-ccw] That sort of thing (C14b – inexperienced user)*

Specific issues, cases and controls

The fact that parents of older children were particularly satisfied can denote any of several things. As we discussed in our methodological considerations, the older children in our study were more likely to have acquired deafness after the age of two (subgroup-A). It may hence be that children who became deaf after they had acquired some language, do better than those who did not. Alternatively it may be that satisfaction is related to revalidation time. The older children had more experience with the implant and literature suggests that improvements continue years after implantation. A third factor that may play a role is the language environment of these children. Perhaps the older children over-represent children who attended oral schools for the deaf and whose parents were highly oral oriented. This latter suggestion did not appear to be the case however. Ten children were 10 years of age or over at the time of the interview. Indeed this number included four children (C1a, C3b, C4ab, C9a) who were strongly orally motivated but also 6 children who attended a signing school for the deaf (C5a, C6, C7a, C10ab, C12ab, C15).

Conclusions

In general implant results took a while to materialize. The earliest result reported by parents was a general change in behavior; more specifically the implanted child became less introverted into his or her own world. Rudimentary environmental sound awareness was also reported, which triggered an enterprising attitude and which allowed the child to be called by voice. In due course this awareness of sound appeared to expand into voice activeness as well. Most children eventually learned to produce words, some even small sentences while the intelligibility of speech also increased. Some parents felt that deaf school was no longer the ideal environment for a deaf child with an implant and considered a transfer to mainstream education. Yet most parents kept their child at deaf school for quite some time. During the early years after cochlear implantation most parents persisted to speak about their child in terms of the psycho-emotional discourse characteristic of DC-ID.

The experience of parents of older children in this study reveals that progress continues over a course of years. About half of children with at least 18 months of implant experience attained "excellent" spoken language skills, while four attained only "marginal" skills. No matter the level of speech proficiency, most parents felt that their child was able to make him or herself understood in hearing society. This seemed to bring about actual engagement in hearing society. Yet it always remained rather clear that the implanted child was disabled, particularly when the implant was not used. From the perspective of the older children themselves it also appeared that the implant was a success. Most children valued the device and most used the implant during the largest part of the day, though several did not always use it during weekends or vacations.

Compared to parents of younger children, parents highly stimulated the use of the implant.

Children disliked several aspects of the implant. They depicted its size and the way it limited them in their play. The visibility of the device was also not appreciated. Loud and high pitch sounds in particular were sometimes found irritating. The liabilities reported are congruous with Kelsay and colleagues (Kelsay 1996). Post-implantation, the most cited comment on the implant pertained to the awkward size of the speech processor, though the number of parents reporting no disadvantages at all grew steadily to 52% at the three-year benchmark (Kelsay 1996). Still most children developed a satisfactory "relationship" with the implant device. It appeared that the degree of spoken language proficiency was negatively related to the use of Sign language in the child's environment.

Judgment on benefit was dependent on length of implant use. Shortly after implantation it seemed that parents were generally not bluntly positive about the device given the meager results. Parents of older children were generally content yet were aware of inter-individual variability as they hesitated to make a general statement about implants based on their contentment. Yet quite a few parents were more reserved in their opinion. It seemed that implant results were not so grand that it erased their doubts regarding the future: failure remained a concern. Yet it also seemed that, while parents may not have *expected* unrealistic outcomes from the procedure, their *hopes* transcended the limited expectations. Parents had hoped for better spoken language skills and improved opportunities for educational mainstreaming. Disappointing results were rarely attributed to a lack of spoken language revalidation. It appeared however that disappointment resulted from the fact that expectations were shifted upwards in light of the new problems that parents of (pre-) adolescent implantees encountered. As we discussed in the previous chapter, many parents aspire to provide a good mainstream education for their child and safeguard future opportunities. When contemplating these goals, parents encounter an array of problems in spite of most successful implant use. It may hence be that dissatisfaction does not so much relate to judgment on implants but sooner to the general situation in which parents have to find a way to realize their goals. Indeed it appears that "uncertainty" is the lot of parents of a deaf child.

> Jascha was 18 months old when my concerns over his hearing were confirmed. That is almost 12 years ago today. It was a beautiful day, just like today. I still remember the images from that day clearly. [...] It was the day that my world was turned upside down. The day that my world turned out to be a different one than that of my child. [...] And look, our lives have turned to normal after all. The consequence of having become wiser, milder, more easy-going? Or a matter of habituation? That certainly has something to do with it. In twelve years time one can get accustomed to a lot of unusual situations. Because deafness remains unusual and a lot of the problems have not disappeared. What has changed is those two boys. They make their way through life as deaf, more and more in their own way rather than the way I had planned. [...] It will be fine, I think even though

the world is still as hostile towards the deaf as twelve years ago. [...] I am on track, but where does it lead? (Hiddinga 2001 – translation ccw)

DISCUSSION

What we learned in this chapter is that no distinct moral dichotomy or "differing conceptions of the good" explains why some parents did while other did not choose for a cochlear implant (Murray 1997). As we have argued, most parents appear to depart from a similar value set, which in its most elementary form may be said to consist of four elements. Firstly the desire that their child will be happy today as well as in the future. Secondly, that their child will reach a certain level of autonomy, which in its most elementary form consists of the ability to function in society without being dependent physically, mentally, financially and emotionally on others too much in providing at least the basic needs of life. Thirdly, they hope that their child will encounter opportunities, which materialize mostly as opportunities to cultivate as a person. A good education, job opportunities and socio-emotional opportunities are roughly derivatives of this broader value. Last but certainly not least, parents wish to experience an intimate relationship with their child and hope that this relationship can be maintained throughout his or her adult life.

Based on these general preferences, most parents would likely theoretically choose for a cochlear implant, *if* the implant were perfect and produced no liabilities in terms of what parents valued. Though parents are not convinced that such an implant would make the child happier per se, they are convinced that it would best serve autonomy, opportunity and perhaps also the parent-child relationship. Yet the implant is *not* perfect and does have distinct liabilities, something all parents were very much aware of. Hence, deciding what is best for an individual deaf child cannot be explained by these "general preferences" alone. After all, some parents actually do not choose for an implant.

> For even if the probabilities of the occurrence of the various possible outcomes of each option are accurately known, there may be no uniquely rational estimate of the relative value or importance of the harms and benefits. (Buchanan 1989, 252)

In order to reach a concrete decision, local factors play a crucial role as we discussed in previous chapters. These factors include the context of the child. Yet they likely include parents' "interpretational frames" as well. It could be mechanically argued that the former provides the object, while the latter functions as the instrument measuring the object. Parents' interpretational frames shape the way in which the concrete reality of the child is fitted into their value set. The task parents face is to determine to what extent their values are "reasonable" within the context of their child. The question that parents ask themselves is primarily how to weigh the chance that their child will gain in autonomy, opportunity and parent-child bonding versus the chance that he or she will not. Secondly they ask themselves how to weigh the sub-optimal situation that the implant will possibly lead to, hence how to balance the gain it will induce versus the liabilities it will produce. In the case of a perfect implant the issue of "reasonability" would play an insignificant

role. Several factors come into play in determining how parents went about such an appraisal.

Knowledge of the potential of cochlear implants as well as its liabilities play an important role in this process. Knowledge of and confidence in cochlear implant technology was a modifier. This was the most obvious in some controls who, because of the advanced age of their child, were not aware of the option of cochlear implantation. Most of the control parents whom we interviewed were the parent of one or more deaf adolescents. Cochlear implants became available for Dutch deaf children in 1990. It appears as though widespread knowledge of cochlear implants was not present in these early days, certainly not for those parents not residing in the direct vicinity of one of two implant teams. While parents from the IvD area did commonly possess information early on, this appears not to have been the case for those attending the Amman school (Amsterdam) or the Guyot Institute (Groningen). Knowledge of dissimilar management of profoundly deaf and hard of hearing children often instigated the process of de-essentializing the cultural view on deafness. Indeed what parents realized here is crucial. It is well documented that people with slight to moderate hearing impairment (27-70 dB) do considerably better academically than those with severe or profound losses: the difference in language terms being 3 to 6 years by the age of seventeen to eighteen (Paul 1987; Paul 1990a; Ross 1982; Moores 1987). Indeed, the hearing threshold has not only been known to be an important confounder of oral language proficiency, but of academic achievement as well (Cowen 1981). Similarly, parents observed that at most deaf schools, hearing aids were advocated strongly, which established a link with the implant if hearing aids failed to yield any advantage. While some authors have suggested that children with hearing losses below 100 dBHL should be submerged in a Sign environment as well (Preisler 1997; Johnson 1989) and manually coded language is certainly employed in education of some of these children, it seems that the acquisition of spoken language is considered much less controversial in this context. Since some hard of hearing children enroll in signing deaf schools, parents of profoundly deaf children come to notice these children and notice how they are approached differently, both educationally as well as normatively. The latter implies that they do not only notice how deaf children are offered a different curriculum; they also sense that the school board prepares these children for a different "socio-cultural life" so to say. Indeed Levy-Shiff has found that the greater the hearing impairment, the greater the tendency to segregate (Levy-Shiff 1985). While profoundly deaf children receive only a minimum of training in spoken language (most parents of signing deaf schools report 3 sessions per week of 15 minutes - which we verified to be correct), hard of hearing peers receive more attention to these skills. Parents experience this difference as confusing at first. Parents deduce from this policy that the DC-ID view is in essence pragmatically grounded, despite its foundational tone. "Accepting" their child's deafness, a theme most all parents are confronted with intensely, is hence de-linked from its specific content casu quo that content is identified as socially constructed (Modell 1997; Rycroft 1992). Some parents of implanted children disclosed that the discovery of the significant prognostic difference

between groups with losses below 100 dBHL and those above that level with respect to spoken language acquisition and the finding that their child performed very low on these tasks, triggered interest in cochlear implants Hence, a crucial step many parents of implanted children eventually make is that they come to question the representation of the choice for an implant as a moral choice vis-a-vis their child's essence - hence they reject the meta-theoretical foundational grounding of DC-ID and focus pragmatically first (Paul 1993, Parker 1997)

Yet, knowledge in itself is not sufficient in understanding the process What is conceived as "significant gain" and what is conceived as "significant liability" is dependent on subjective thresholds to some extent Some parents may for example decide that only the rate of success of the top achievers with an implant counter-balances the liabilities sufficiently while others may be satisfied with less success Parents who are emotionally sensitive to the idea of sub-optimal social functioning, may judge their child differently than those who are more permissive about this This parental panorama may be in part biographically determined Yet there are other factors beyond biography that potentially impact parents' view It is clear that parents do not stand alone in the decisions they make vis-a-vis their deaf child They will encounter opinions of family, friends and other acquaintances They will be informed by journals, books, and movies and will grow into an environment of teachers, social workers, adult Deaf individuals and other professionals It is more than likely that these external factors will be of influence on how parents decide If for example, emphasis is put in the "half empty" nature of implants this may result in different appraisals as compared to a "half full" approach Both cases as well as controls expressed to value spoken language skills equally It may be however that detailed technical information is not mandatory to reach a decision parents may find enough support in a gross verdict on implant efficacy – "effective enough or not" It seems that the latter is most prevalent in parents attending one of the signing schools while the former is most common in those attending IvD Parents who chose for an implant perceived the chances for language acquisition quite positively Parents who did not option for an implant on the other hand, held more negative opinions in this context Parents whose child attended one of the Sign-oriented schools were most ambiguous These parents commonly persisted in the psycho-emotional discourse common to DC-ID It appeared however that the persistence of this discourse was pragmatic in origin When children make little headway in spoken language terms, the DC-ID narrative is re-employed by parents Yet parents do so in light of the perceived inability to realize the goal of spoken language This shift in moral frame is neither strange nor unique to deafness A similar capacity of people to adjust their moral discourse conforming to reality or local circumstances has been shown in different contexts The concept of recall bias covers this phenomenon As illustrated by several studies, patients have the tendency to reshape their moral discourse depending to the local situation

By 1990 most respondents had already made significant educational choices for their youngster Their deaf child had been enrolled in a deaf school and most parents had

chosen manual coded language (NmG or NGT) as their primary mode of communication at home. Cochlear implants were to some extent experienced "at odds" with these choices and the stability or security that parents had found in them. This makes the choice for an implant much more than a choice for an implant, but rather a choice for renewed uncertainty When implants became available many parents were generally satisfied with their direct situation While this is not to say that they did not have any critique on deaf schools or that they did not worry over their child's future, they considered any deviance from what they had as an unequivocal risk. Hence, parents were typically satisfied with the functioning of their child, yet this functioning was experienced as fragile, making any change of path risk full

> One good reason to discount the future somewhat is its uncertainty We know less about the future than we do about the past and the present A bird in the hand is worth two in the bush (Bell 1998, 307)

People deal differently where it concerns risk-taking and facing uncertainties, which may as such be a factor of influence (Buchanan 1989) Particularly if a value of high emotional meaning is involved, such as one's own child, these strategies may be of interest The choices faced, be it educational or a cochlear implant are not backed by guarantees The choice for an implant cannot be delayed infinitely and a bicultural environment may not be changed to a more oral environment if spoken language confirms not to develop

Many parents appeared much aware of and remained sensitive to DC-ID arguments, most noteworthy of which is perhaps the implicit threat made to the continuity of the parent-child relation (Eldik 1998). Parent who deviate from the Deaf culturalist route, for example by having their child implanted, by placing their child in a school for the hard of hearing, by mainstreaming their child, by providing additional speech training or by demanding better education, experienced the fear of being rejected by their child in adolescence or adulthood. The operation itself became the focal point of the ambiguity that surrounded the implant decision and became the target for DC-ID's acceptance discourse. For most parents this appears to have been an emotional experience. In this context, changing a "physical trait" of a child appeared to be experienced as a symptom of conditional rather than unconditional love - particularly since this trait is made relevant through DC-ID discourse. The specific character of the cochlear implant procedure - its localization in the head and its involvement of the senses - may have been experienced as particularly alienating by some parents. It may appear that the locality in the head - although strictly speaking incorrect since the main cochlear implant component is positioned in between the skin and the skull rather than inside the skull - and the aim at the senses leads to connotations of identity and essentialism. Particularly in the context of the deaf, where parents are actively confronted with a discourse that convicts them of intolerance, it may well be that some parents choose against cochlear implants to dodge these accusations.

It is interesting to investigate the resistance that cochlear implants have stirred in wide circles. It seems that one potential component of this resistance alludes to the nature of the procedure itself. Dutch essayist Karin Spaink has argued that prosthesis in general are received with disgust. She interprets this repugnance as follows:

> Examinations and prosthesis are odd and uncomfortable things. In one sense they are much alike: they externalize physical functions, bring them from the hidden inside of the body to the outside that everyone can see. [...] The Center Pompidou in Paris achieves the same in its architecture...Beaubourg's architecture is compliant to the disability logic, it is a wrong building. Beaubourg was experienced as shocking. (Spaink 1993-translation ccw)

While the externalization of physical functions in itself may induce a sense of aversion, an added factor may be the fact that functions are not only externalized by a prosthesis but also express mechanization and dependency and as such breach both the "silence of the body" typical of able-bodies, but also the sense of holism with which able-bodies experience their bodies (Wever 1997). The first alludes to the lack of conscience that our bodies are *all* fragile and finite. The confrontation with people with a visible disability confronts us with this and may as such cause distress. The latter alludes to the way we experience our bodies as integrated with the self rather than an anonymous composition of biological organs, cells and physiological functions. The fact that the decision to implant is made by adult parents and that the procedure is subjected to young children, universal symbols of purity, innocence and vulnerability, may further fuel emotion (Eyer 1996). All in all, implants may contribute to a sense of what some have labeled "dehumanization" (Sassower 1997). The importance of this observation is that people who are struck by alienating emotions over cochlear implants may speak a "different language" altogether. A good example of this possibility can be witnessed in a wide array of cases where dehumanization is operated as an argument. In a television debate on Electro Convulsive Therapy (NCRV Rondom Tien, 19/01/99) such a confusion of tongues could be observed. While proponents of ECT argued in medical terms and underscored the lack of humanism of withholding chronically depressed patients a valuable treatment, opponents were adverse to medical data and structured their humanist opposition around concepts such as "elegance" and "esthetics". In addition, reference was made to the 1960s when ECT was a widespread practice and when ECT was indeed imposed *forcefully* on patients - something that was visually recognizable since at that time the procedure was not performed under general anesthesia. Regardless of treatment efficiency, opponents of ECT rejected the abhorrent esthetics of the treatment which they felt was deeply dehumanizing: "we have to draw a line somewhere", one opposing psychiatrist argued. It could be argued that this assertion is not unlike the one operated by opponents of unrestrained technical medicine in the 1950s and 1960s. Van den Berg has portrayed a young man amputated to the belly as the disgusting culmination of such a transgressing medical practice in his influential publication Medical Power and Medical Ethics (van den Berg 1969). Nonetheless a distinction must be made here. Even though van den Berg does confront us with the esthetic horror of some medical practices, his position stems equally from pragmatic assumptions on quality of life: indeed he resents

the dehumanizing nature of the case in question in itself, but his position acquires its argumentative power by also questioning its assumed *benefit*. His implicit message hence seems to be twofold: "how can we do this to man?" but also "how can we expect man to live like this?". It is this last question, which is lacking in convincing power in the context of ECT as well as cochlear implantation and thereby weakens the case somewhat. Facing convictions of esthetic dehumanization, proponents of both techniques situate the "humanism" of the technique in its outcome. Psychiatrists who practice ECT do not deny the dehumanizing image of what they do, but assert that no effective alternative exists. Similarly, implant teams argue that a productive alternative is lacking. This may explain in part why the cochlear implant debate has come to evolve over the latter assumption. Is there a productive alternative? Yes, opponents argue: Deaf culture. Parents who optioned for a cochlear implant however as well as some who did not, appeared to draw this view in question. They seemed to unveil the unspoken and never established presumptions of "best interest" by Deaf culturalist and conclude that they are unproven or unknown, at least as unknown as the assumptions of cochlear implantation benefit (Mnookin 1979). Some authors have taken the argument one step further by persisting in their esthetic humanist argument. These authors are adverse to the other side of the coin. The question of a viable alternative does not interest them really, rather they feel that "lines have to be drawn" and base their position on metaphysical assumptions. This typically includes moral statements such as "we as a civilized people do not do this to others". In the context of cochlear implantation this translates to the statement "true loving parents do not do this to their child".

As we have described in the previous chapter, parents' values and goals change over time. While parents of young children are inclined to focus on gardeningship values such as emotional well-being, in time parents come to focus on safeguarding a child's future window of opportunity. Parents of deaf children are no different in this context. They too strive to create an environment that will best cater a child's ability to stand on his or her own. In this chapter we have seen that this general thesis, is highly relevant in the context of the cochlear implant decision. Parents clearly place cochlear implantation in their roles as guardians. In terms of guardian values the "problems" of a deaf child are rather simple: he or she does not hear. To improve hearing is the solution to this problem within a simplistic scheme. Yet skeptics have warned that cochlear implants may not be an adequate solution in this context. As Lane has argued extensively, cochlear implants may fail to yield the kind of improvements in hearing that we seek (Lane 1995). Indeed we generally did not find our respondents to be unabridged positive about cochlear implant results. It appeared that dissatisfaction or at least restraint was rather common when evaluating cochlear implant results: even if results appeared rather excellent, many parents were not wholeheartedly satisfied. How can this be explained? Does it lead to the conclusion that skeptics such as Lane are right in their assumption? Not necessarily so. It may well be that the so-called "moving target theory" explains this finding. The moving target theory is based on the finding that people are "naturally" inclined to upgrade their desires as their context improves.

> The more we get, the more we want We manage to keep ourselves dissatisfied, no matter how much better off we become This is an old story in human affairs (Callahan 1994, 252)

Based on this theory it seems that hopes and expectations have the natural tendency to persist rather than to consolidate or taper at a certain level The most illustrative example of this theory is perhaps that "desired income" is dependent on "actual income" People who earn let's say € 25 000 per annum on average feel that it would take € 50 000 to be able to realize all their desires, while people with an income of € 100 000 feel that € 250 000 would satisfy their needs In the context of cochlear implantation this would suggest that hopes are shear endless and increase with every improvement of outcome, which would relativize parents' dissatisfaction to some extent While parents may persist to hope for more even if their child successfully graduated from college, it appears that at some point the role of the implant in this matter intersects other factors of influence and becomes much like "normal" parents desire for higher outcome

It seems fair to conclude that, by current standards, some of the more experienced children in this study functioned at ceiling-level, implying that no additional benefit can realistically be expected from the cochlear implant device Nonetheless their parents continued to experience difficulties that resulted in discontent Hence what the tale of more experienced parents teach us is that things are not as uncomplicated as the simplistic scheme suggests Even if some hearing is restored through cochlear implantation, spoken language does not develop by itself, does not develop substantially if serious speech therapy is ignored Even if spoken language does develop substantially, mainstreaming remains a considerable problem for many children and required serious efforts by parent, child and school to realize Even if spoken language does develop substantially, social engagement in the hearing world remains problematic and fundamentally uncertain Implants cannot and likely will not restore hearing to normal, implying that difficulties will always persist

This chapter shows that parents reason pragmatically and child-centred rather than departing from a deontological foundation when considering cochlear implantation Similarly to what we discussed in the previous empirical chapters, it seemed that parents were highly sensitized to the issues, to the conflicting values involved and the uncertainty of the outcome and were constantly re-evaluating and prepared to undertake action and change Parents were certainly not guided by a rigid attitude, by prejudice or resigned coping but were rather attentive, responsive, flexible and creative From this it seems unreasonable to uphold the hypothesis that parents respond to coping difficulties or to a blind desire to "normalize" their child It also seems that their pragmatic child-centred position is rather agreeable from a "process" point of view, even though we cannot exclude the possibility that parents over-estimated their child's potential to be challenged and his or her resilience to cope with the stresses that may or may not be induced by such challenges

Nonetheless, deaf ecology seems to feel that parents are making some severe mistakes in terms of their new "self-willed" perspective on deafness – as the disagreement seemed only to rise rather than subside when the issue of cochlear implantation is introduced. Deaf ecology seems to categorically reject parents' child-centred pragmatic approach, or seems to at least feel that they are blameworthy of using a too narrow or too unrealistic scope in judging their child's circumstance. The concept of "acceptance" modulates this opinion, through a variety of ways. The most fundamental form of CI critique is formulated by DC-ID. As we have shown, parents disagreed with its portrayal of deaf children as children with a pre-determined identity. They renounced the idea that their child can only become "what he or she intrinsically is" rather than "being what they will become", and they used a range of arguments to support this view. Still, we have ourselves refrained from an analysis of the claims of Deaf culturalism, while they are rather crucial to our mission. However strongly parents may disagree with DC-ID and however sympathetic we may be towards their claims and their general attitude as parents, *if* its arguments are valid from a moral point of view, a pragmatic child-centred approach may indeed be questionable. Pragmatism implies and necessitates and agreement on or at least mutual understanding of the moral issues at stake. As such to simply move forwards to pragmatism before the moral issues have been discussed is rather unsound. A single look at one of the many heated ethical debates can readily illustrate this: however extensively and prudently euthanasia guidelines are formulated, many are still in rather foundational disagreement. Yet even if we would agree that Deaf culturalism is "inappropriate" in the case of deaf children and agree that we should look at cochlear implantation from the vantage point of what "benefits" a deaf child best, we need to be more informed about which values are at stake when we seriously want to judge these children's situation from a best-interest approach. What do we mean when we speak about "benefit"? Can we find common ground in talking about "benefit"? Is our regular way of thinking about "benefit" applicable to the case of deaf children? Without answers it will prove sheer impossible to say anything about the cochlear implantation reasonably, or at least with any hope of mutual agreement. This requites that we look deeply into the claims of Deaf culturalism as well as into the general literature on child advocacy and "best-interest". In the next chapter we will fulfill both of these requirements, which as such will draw the moral space for our final ethical discussion on pediatric cochlear implantation in chapter eight.

PART III

CHAPTER 7 – DECONSTRUCTING DEAF IDEOLOGY

INTRODUCTION

In the previous empirical chapters we have outlined parents' experiences with deafness in a rather chronological way. We have argued that to understand parents implies understanding their local situation, their role and values as parents and the interaction with their deaf school environment. In this context, we described how parents slowly developed into self-willed parents who more and more came to view their child pragmatically and on his or her own terms, and as such increasingly dissented from the deaf school protocol. Parents developed from predominantly gardening-orientated into more guardian-orientated parents and believed that the outlook of a self-reliant future ought not a priori be excluded from the life of deaf children.

Synchronous with this change in perspective, the deaf school environment appeared to *fortify* its arguments and shifted from pragmatic arguments to the moral arguments of DC-ID, most evidently through its opposition to cochlear implantation. Hence, deaf schools seemed to reason that parents' self-willed pragmatism was inappropriate in one way or another. In the previous chapters we have attempted to elicit the premises of the DC-ID argument from several angles, and it appeared that the concept of "acceptance" modulated much of the critique. We illustrated that parents of older children recognized and analyzed the premises of this argument and formulated their opinion opposed to it. Parents resented how DC-ID reduced their child to his or her pre-scripted condition, and felt that such a view was rather inappropriate from a pragmatic vantage point. Yet so far we have refrained from commenting on the content of DC-ID, while it is rather critical from an ethical perspective. As we explained in the previous chapter, we cannot simply discard the moral claims that Deaf culturalism makes and proceed with a pragmatic analysis without thought – certainly not if one aims to find common ground. Moreover, even *if* we decide that a pragmatic best-interest approach is the most suitable, we still face conceptual obscurity and potential disagreement: we need to make at least an attempt to find common ground when talking about deaf children's best-interest, if we want to proceed to analyze how the "facts" - however scarce they may be - relate to these interests.

Acceptance was a key argument in this context, a concept on which most of DC-ID's arguments hinge really. Yet we have shown that the exact meaning and implications of the call for acceptance often remained implicit: sometimes this call appeared as rather foundational, while at other times it seemed to represent pragmatic disagreement. As such we will first critically discuss the acceptance discourse in this chapter, to open and scrutinize the moral register of the DC-ID discourse. Since Deaf culturalism is believed to originate in the United States and since it is closely related to the minority debate in that country, we will draw parallels to the lively debate on the state of American minority politics, a debate in which many of that country's most prominent philosophers have actively participated. The key question here is: is the moral-political case of ethnic

minorities applicable to pediatric cochlear implantation, as Lane and many others have suggested, and are we therefore to refrain from cochlear implantation on foundational grounds, ergo even if a "perfect" implant were available?

Next, we will discuss the implications of viewing the case of deaf children from a pragmatic "best-interest" vantage point, in an attempt to clarify our concepts and to find common ground in terms of which values are at stake and how we should proceed to evaluate them. We will review this issue from the perspective of general child advocacy, which will instantly expose the complexities involved as well as the disagreement that divides child advocacy across political-philosophical lines – which will make it rather clear that, even in the case of general child advocacy, common ground may be further away than hoped for. Furthermore, we must ask ourselves the question if the paradigm of general child advocacy *can* be applied to the case of deaf children uncomplicatedly. This is a pivoting question, we feel. We will draw on the case of profoundly retarded children to show that to uphold the paradigm of general child advocacy can have some very unpleasant implications indeed. We will also show however, that to dwell on these implications too much and with too much disregard for context, can be equally devastating to the best-interest of deaf children.

This will finally lead us to an assessment of the "appropriateness" of DC-ID arguments in the context of deaf education and cochlear implantation, to so define the "moral space" from which we will proceed to analyze the cochlear implant debate in the final chapter. The contents of this chapter should explicitly not be read as an encompassing discourse, since this neither corresponds to - what we believe is - the complex nature of the material under scrutiny nor to the profoundly groping effort that it took to realize it.

THE MORAL SPACES OF ACCEPTANCE

Introduction

The notion that parents ought to "accept" their handicapped child surfaced lavishly throughout the previous chapters, and as such seems a determining argument in creating a specific moral space on deafness, a moral space that more or less appears to preclude cochlear implantation Yet as we have shown, the call for acceptance can hardly be perceived unambiguously acceptance appeared in a variety of meanings, in various discursive spaces and it often seemed as if these meanings were overlapping rather confusingly As discussed in chapter three and four, acceptance occurred in the context of coping theory In chapter four and five we revealed that acceptance also emerged in the context of DC-ID, as it referred to the concept of "unconditional love" and "tolerance" vis-a-vis Deaf culture All of these arguments re-surfaced in our chapter on cochlear implantation Especially the latter arguments were shown to be vital in "retaining" parents to the prescriptions of deaf ecology

The moral spaces of "acceptance"

- Psychologically "constructive" coping
  - Constructive coping requires the release of the coercive grip of the prejudiced view on disability
- Unconditional love and child-centeredness
  - "Good parents" ought to love their child regardless of his or her traits
  - "Good parents" ought to be child-centered and aim to optimize the socio-emotional well-being of their child first and foremost
- Identity and culture
  - Pragmatist Deaf culture is the unanimous and positive choice of deaf adults and as such the likely choice of deaf children as well
  - Foundationalist Deafness is a cultural identity constituting trait and "good citizens" ought to respect such cultural identities

In spite of the fact that distinct discursive spaces can be identified, this distinctiveness was rarely encountered in our material Rather "acceptance" appeared to function as a *global* concept to which most parents were sensitive In this section we will analyze the concept of "acceptance" from the abovementioned three separate discursive spaces This will lead us to a fourth implication of acceptance, namely in terms of a child's "best-interest"

Acceptance as coping

Theories of loss and grief are psychological or psychodynamic theories, which focus on how individuals respond to the loss of significant objects (Pollock 1994, Kubler-Ross

1969, Bruce 1996 Engel 1961) As such these theories provide the framework for "normal" versus "abnormal", "uncomplicated" versus "complicated" or "physiologic" versus "pathologic" coping The main coping assignment has commonly been defined in terms of "task completion", specified as the "revision of inner models, schema's, or assumptions held about the world" (Bruce 1996, Bruce 1994) As an example of abnormal development, such theories operate concepts such as persistent mourning, chronic sorrow or unresolved grief (Jacobs 1993c, Pollock 1994) Though these concepts may impress as an arbitrary and potentially normative judgment, this need not be the case per se in clinical psychology and psychiatry the emergence of specific psychiatric problems such as depression, anxiety, substance abuse or posttraumatic stress disorder can be operated as an "outcome criterion" (Jacobs 1993c) Indeed if it can be shown that people with a specific coping style are at risk of developing severe psycho-emotional problems and if it can be shown that the two are causally related, the conclusion that these coping styles are unwelcome seems comprehensible if the result of a specific coping style is that people end up in a position in which they cannot handle the demands of life reasonably, it seems logical to aim to prevent such an event and to classify it as at least "non-constructive"

It has become quite common to inquire into the early responses of parents with handicapped children through psychological theories of loss and grief, or at least through its normative frame of "constructive" versus "non-constructive" coping (Flagg-Williams 1991, Bruce 1996, Bruce 1994, Simons 1987, Darling 1983, Reinders 2000) Theoretically, this inquiry is intelligible parents are assumed to experience severe emotional grief over the fact that they have "lost" the child they had, be it physically in the case of an acquired disability or imaginary in the case of congenital disability (Hindley 1993, Meadow 1968b) Nevertheless, in deaf studies it has not so much been this grief itself that has caught the interest, but rather its possible relation with how parents *decide* for their child (Bruce 1994) Again, this is rather understandable grief over deafness is experienced by a parent yet involves a concrete other, and as such those concerned with the well-being of this "other" may worry that parents' grievance influences the quality or "constructiveness" of their decision-making negatively Thus given the "proxy" context, it seems reasonable to include the welfare of the child when evaluating coping "constructiveness" parents' decisions may for example reflect their desire to deal with their own agony rather than with what benefits their child the most

Yet, while few would contest that outcomes such as depression or anxiety are "non-constructive" and as such the result of a psychological process that we would want to avoid, this is *not* so self-evident when we focus on specific parental *decisions* This is the Achilles-tendon of the way that coping theory is operated in deaf studies the suggestion of "non-constructive coping" only works if specific decisions such as an oral language orientation are classified as "negative" in terms of the deaf child's well-being The latter is often assumed as a "given" however, rather than forming the backbone of the argument Therefore the threat of judging individuals based on normative grounds is

rather real (Eyer 1996, Bruce 1994) Indeed this has led Larson to the opinion that acceptance is a "blanket term", used intensively by health professionals yet inadequately reflected upon (Larson 1998). Jaehnig also speaks of acceptance as "part of an arsenal of concepts which professionals are prone to use when they sit in judgment on the family" (Jaehnig 1974; Philp & Duckworth 1982).

One may on the other hand uphold the psychological root of coping theory, rather than the pragmatic focus on outcome that we discussed above. It may very well be that some parents utterly fail to come to terms with their child's disability and as such manifest "pathologic" rather than "non-constructive" coping. While one may still argue that the reasons to disapprove of such coping strategies should be viewed in terms of the unconstructiveness it yields for parents' and child's lives, the "phenomenology" of severe grievance may be so intense that it appears almost self-explanatory One could subsequently argue or even observe that such brokenhearted parents are predestined to strategies that are blindly aimed at "resolving" the disability While such strategies are not by definition "unconstructive" from the child's perspective, they *can* be indeed. parents that insist that their quadriplegic child should not use a wheelchair may be argued to support such a judgment. As such, the self-evident phenomenology of *extremely* suffering parents and their "typical" action orientation may become intertwined, drawing the question of how constructive a *specific* action really is in terms of a child's best-interest to the background. Therefore, it could be that the focus has been too much on those parents that utterly "fail"

> Much of the early, clinical, literature on parents of handicapped children focused on parents who did not adjust As a result, the pathological attitudes of a small minority came to be seen as normative for all parents of the disabled (Darling 1983, 141)

So how were our respondents doing from this coping perspective? We suggested that an answer to this question is dependent on time factors. Much as has been described for people who suffer from a chronic disease or physical disability, "experience" is a crucial factor here (Wever 1997). We would suggest that in the earliest days of deafness parents have not developed an experience-based model of their "actual child" while they *do* have command of a stereotype of deafness or disability. In terms of Isarin, parents lack an image of the "who" of their child yet do have command over information about the "what" of the disability This "what" may be equated to the negative social image of disability Yet this image is rather unattractive and "unconstructive" since, given the negative connotation of this image, it may come to stand between parent and child (Isarin 2002). Since parents long for a loving relationship with their child, this unconstructiveness may be argued to be a strong impetus for change Through the passing of time and the growth of experience, the caricature image fades or is remodeled, a process that ultimately leads to an experience-based concept of the "actual child" (Frank 1991) Eventually, this actual experience comes to overshadow the dominant social disability image of deafness. Parents' everyday experience with their deaf child - in

particular experiencing the joy, the lack of self-pity and the relative prosperity of the child - slowly overshadows the internalized social stigma of deafness. This experience may be said to yield a second narrative which is much more positive. Parents become honestly content with their child's emotional functioning and with their relationship with the child.

Thus, given the lack of overt suffering, the lack of a blind persistence of the prejudice caricature on deafness and the success in terms of developing a satisfying and loving relationship with their deaf child, we feel that it is incorrect to assume pathologic or unconstructive coping, at least from a parental perspective. Parents seemed able to relativize the negative prejudice view on deafness, at least in terms of their relational experience, which was positive indeed. Parents did not experience their child as pitiful and were disturbed by others who insisted this view upon them. Parents stood open for change and were highly action-oriented, which was most obvious through their rapid and unanimous choice for Sign language. Indeed some authors have claimed that the majority of families adjust to their circumstances quite well (Darling 1983).

Acceptance as unconditional love

Yet as we also illustrated, parents did not *welcome* the situation that they were confronted with, as they episodically continued to resent deafness. It seems however that "welcoming" is not necessarily a requirement of "constructive coping" as discussed in the previous paragraph. When we consider coping in the context of actual decision-making, be it for the self or by proxy, we are concerned with the appropriateness of the decision primarily. The persistence of grief did not appear to exclude joy in child rearing nor the flourishing of authentically experienced love for the child. Thus parents' intermittent resentment of deafness did not appear to have tangible influence on the establishment of a satisfactory and authentic child-parent relationship, nor did it seem to yield parental shame or pity (Eldik 1998). Therefore it seems that parents do not need to "welcome" deafness in order to reach appropriate or "constructive" decisions: to "cope" with deafness is not identical to "welcoming" deafness. As a matter of fact one could even suggest that "welcoming" deafness can be rather "unconstructive" since it denies the real limitations that the condition generates and as such may lead to decisions that do not benefit a child's well-being. When we *do* equate the two we silently yet decisively trespass the line from a coping perspective to the moral perspective of "unconditional love".

In the previous chapter we illustrated that DC-ID links the issue of "acceptance" to "unconditional love". Yet we should be aware of the fact that we are now talking about a different form of "acceptance" really, a form that has little to do with coping theory in itself but rather with parents' "attitude" or "moral character". Indeed Hays has shown that modern "intensive" parenting ideology is strongly influenced by the demand of a

parental attitude that is self-sacrificing, child-centered and non-demanding (Hays 1996) Clearly, deaf ecology exploited the cultural value of unconditional love and prescribed exactly which decisions were to be perceived as the hallmarks of such a virtuous attitude *any* resentment over deafness and *any* consideration of spoken language or socialization beyond Deaf culture were depicted as signs of "conditionality" Contrary to coping theory, in which judgment is dependent on the constructiveness of specific decisions, acceptance as a virtue does not require such scrutiny Its legitimization lays not so much with the appropriateness of the outcome, but with the *intention* of the beholder and the moral symbolism of specific actions The intention of the beholder should be unconditional love, while the actions of Sign language and Deaf culture submersion are depicted as morally-symbolically relevant in this context We will explore the latter issue - why specifically Sign language and Deaf culture submersion are selected as "relevant issues" in terms of a parent's moral character - in more depth in the next section

The demand of unconditional love and the prescriptions of DC-ID makes intelligible why many parents experienced confusion over the fact that they episodically continued to mourn over deafness This experience has been described in terms of ambiguity or paradox

> Yet, while I grieve, I also hold deep love and joy for Jessica, knowing that she is perfect just the way she is It is such a paradox (Marsh 1995, 127)

One could hypothesize that there are three options to deal with this state of confusion

Dealing with the demand of unconditional love

- Accept and embrace the prescriptions of deaf ecology
- Learn to live with ambiguity
- Debunk the prescriptions of deaf ecology

Firstly, one could suppress feelings of grief over deafness and embrace the prescriptions of deaf ecology wholeheartedly, thereby meeting the demands of unconditional love This is probably what health care workers and other advisors mean when they speak of "accepting" deafness By defining the "who" of a child in terms of the unique "what" of Deaf identity, the internal dissonance is resolved, at least in theory it is embracing the prescriptions of this "what" equates to an unconditional embrace of the "who" of the child Deafness, Sign language and Deaf culture are as such defined as morally relevant characters in term of a deaf child's "authenticity", an issue on which we will elaborate in the next paragraph that deals with the concept of "authentic identities" The moral range of the statement is that parents should "accept" their child unconditionally while the details of the statement claim that this can only be done by "accepting" his or her deafness loving a child's deafness is loving the child him or herself As such the "who" and the "what" seem to be fused rather than separated Yet as Isarin states, this is not without problems since it ultimately may lead to a view on the child as a "romanticized other"

> The impulse of the Who will in its most extreme form lead to romanticization of the handicap. In all its untouchable uniqueness the child will become locked-up in itself. The opportunity to be different or more than it is, is eliminated. (Isarin 2002 – translation ccw)

This view is not restricted to deafness or disability of course. Parents of normal children can also be confused over the moral implications of making demands on their "authentic" children in light of the popular cultural demand of unconditional and child-centered parenting (Hays 1996).

Secondly parents may learn to deal with paradox. Indeed, in literature on disability and chronic disease the answer has also been one of cognitive or existential ambiguity: it is assumed that the handicapped individual learns to live with a reality that is not uniform (Kay Toombs 1993). Reinders for example, states that parents "have to reconcile a positive and a negative judgment within their own soul" (Reinders 2000). Eldik also speaks of an "internal ambivalence" to explain how parents report to experience a fulfilling relationship with their child in spite of the vast problems induced by deafness (Eldik 1998).

> Over and over again, when asked what would improve their well-being, all of these mothers wished for miraculous cures, that the child would walk and talk, that the child would be normal. Yet, at the same time, they expressed a deep love and affection for the children just as they were. [...] I learned to make my mind large, as the universe is large, so that there is room for paradoxes (Larson 1998, 869)

March suggests the concept of "Embrace of Paradox" to describe the internal tension that parents experience (Larson 1998).

> I am finally learning to embrace this paradox of joy and grief that I will always hold, rather than telling myself that I shouldn't feel this way. (Marsh 1995, 127)

The third option parents have is what we referred to as "debunking" Deaf ideology's specific claims and prescriptions. Through time parents simply come to experience that the DC-ID claim is invalid as they actually develop satisfying loving relationships with their children. Thus, parents experience that resenting deafness and loving one's child wholeheartedly are *not* mutually exclusive from an experiential point of view. Yet even though this experience was of great practical importance, it is not an adequate answer to the moral claim of DC-ID, which prescribes precisely which decisions are to be perceived as the hallmarks of an unconditionally loving "attitude". To deal with this latter demand requires that Deaf ideology is debunked more fundamentally: the junction of existential child and the definition of "authentical" deafness by DC-ID must be disengaged, parents' attitude towards deafness must be detached from their moral status as "good" loving parents.

Indeed, parents achieved this by de-essentializing the identity claim of DC-ID by separating the "who" from the "what" of their child. Parents detached meta-narratives vis-à-vis the authentical "what" of deafness from the "actual child". Rather, the "actual child" was restricted to an emotional-relational self: to behavior, character, and the relation with parents. A first step parents have to make is to de-essentialize their own demons. The social stigma on disability is a powerful meta-narrative that parents must deal with. The next excerpt illustrates this.

> Karen Klish knew she had "made it" when she picked up the mail one day and found her son John's audiology report in it. John is profoundly deaf, but as she read through the report, Karen was able to say to herself, "That's a piece of paper. That's not John". She could separate John and his handicap. [...] Don't think of your child as a handicapped child'. Think of him as a child who has a handicap. He's a child first, like all children. His handicap is secondary. (Simons 1987, 8-9)

Clearly, what Klish is commemorating here is her victory over the social stigma of deafness, which is symbolically activated by her son's audiology report. Darling has also reported similar findings in the context of parents of mentally retarded children. He quotes one father saying:

> Retardation is not number one around here. It's just something that Karen has (Darling 1983, 132)

Yet in a later phase, parents must *also* deal with the meta-narrative formed by DC-ID. The specific prescriptions of DC-ID were rendered rather insignificant to parents' moral character (Cunninghan 1985; Bruce 1994). Hence, deafness as defined by DC-ID was denounced as a "condition" of relevance to their child's "authentic self" and as such denounced as a narrative that matters in terms of parents' unconditional loving attitude. Having done this, parents eliminate ambiguity in its affective component. As such "dissonant voices" is perhaps a better representation of parents' experience, since ambiguity implies a foggy truth rather than multiple and synchronous crystalline truths that co-exist without necessarily contradicting. We are dealing with synchronous truths in different compartments so to say (Nussbaum 1998; Larson 1998). Isarin comes to a similar conclusion:

> Opposed to the disappointment over the child's limitations stands the pride over little conquests; opposed to the love experienced towards the child as one's own and irreplaceable stands the anger over his slowness, the desperation over what he misses and the sorrow over his incapacity. (Isarin 2002 – translation ccw)

By doing so, parents created the pedagogical room to become critical about the merits of the specific prescriptions and premises of DC-ID. This strategy allowed parents to "work" with a child's limitations without causing uneasiness and confusion. It allowed a guardian perspective to rise to the forefront, as we will discuss in the next section.

Acceptance as "pragmatic" tolerance

A third way in which the concept of "acceptance" arose in our material referred to the concept of Deaf culture. We argued that the concept of Deaf culture was raised mainly as a response to the understood "reality" of deaf adults and the assumed pragmatic inevitability of this reality for deaf children (Lane 1997, Wrigley 1996). Deaf adults share a unique biography, speak a unique language and form a unique community, which is as such perceived of as the irrevocable proof of their unique "ethnic" status The assumed unreserved positivity expressed by Deaf culture members as well as the assumed pragmatic unavailability of a different cultural or "ethnic" sounding board implies that we ought to consider Deaf culture the very likely endowment of future generations of deaf children as well Indeed Wrigley appeals to such a view on Deaf culture as a pragmatic choice:

> The point is that the fragility of the "traditional" channels of cultural transmission, traditional only in the sense of being commonly understood by the dominant Hearing culture, meant that different avenues had to be explored (Wrigley 1996, 27)

Hence, the DC-ID argument is in part pragmatic, since it seems to assume that deaf children will have no other social identity *realistically* available to them besides Deaf culture identity. Furthermore it is claimed that this is *not* something we should regret, since regret is founded on an unsound and prejudiced view on the state of Deaf adults

The adjective "realistically" is rather crucial here After all, the fact that some deaf adults actually *do* self-identify with hearing society may be viewed as a disproval of DC-ID's pragmatic premise that hearing society is simply unavailable for deaf people Yet only very few deaf adults do, which explains Wrigley as well as Lane's position to some degree. one of Lane's central chapters in "The Mask of Benevolence" is titled: "The education of deaf children· drowning in the mainstream and the sidestream" (Lane 1992) Although exact numbers are lacking, it seems fair to assume that the number of deaf individuals that will succeed to live in the mainstream first and foremost will unlikely surpass the number that learns to master spoken language proficiently (about 10% we said). Still cochlear implants at least promise to improve these numbers, hence reintroducing controversy over DC-ID's pragmatic premise.

A likely counter-argument to this assumption is that the merits of these few "successful" mainstreamed lives are brought into doubt – we recall that Lane speaks of "the sidestream" here (Lane 1992). Indeed, as we have argued in chapter one, there seems to exist some skepticism over the merits of the lives that "mainstreamed" oral deaf adults lead, not surprisingly much to the dismay of some of these adults themselves: in the Netherlands mainstreamed deaf adults have joined to form a political platform (SAVON) who's main objective is to "underscore that there are oral deaf people that function fine in hearing society" (webpage SAVON). The concept of "identity" plays a

central role in this skepticism. More specifically, it is assumed that mainstreamed deaf individuals will fail to develop a prosperous and "positive identity" and will consequently "suffer", while those that socialize in Deaf culture will not.

> The quality of life of a deaf person who socializes almost exclusively with other deaf persons, who is educated in schools especially for deaf persons, and whose career is in the field of deafness will be manifestly superior to the quality of life of a deaf person who achieves success independent of institutions for the deaf and of the society of other deaf people. (Stelle 1998 – Stelle rejects this position)

Whether successful in mainstream society or not, deaf people will be "ascribed" a rather negative and defective identity, an "injured self", and would as such be better off with a "positive" Deaf identity instead, as the Deaf-Deaf paradigm is believed to demonstrate. Indeed it has been suggested that this is the likely fate of implanted deaf children as well. They too may find their way to mainstream society, but must still endure the negative identity "badge" of deafness and will suffer as a consequence. Now, one may question this train-of-thought. One may empirically question for example if the assumption of a negative "self-esteem" is indeed inevitable and if Deaf culture can indeed prevent this from occurring. More fundamentally, one may question "how positive" a human life *ought* to be precisely – a question that leads us to political philosophy as we will show.

Perhaps in an attempt to dodge these thorny questions, Lane draws on the example of racial minorities, minorities with a readily visible "stigma". The paragon of racial minorities illustrates the inevitability of a negative identity "badge". Even *if* an Amerindian child would be socialized in Anglo-American culture, our society would still label him or her with the stereotype of his or her race. Much like a mainstreamed deaf person, socialization in dominant culture will not succeed in revoking bigotry.

> Suppose an embryo formed by the union of two Native Americans were implanted in the womb of a Caucasian woman, would the child to which she gave birth be considered Caucasian or Native American? It seems that the cultural membership ascribed to the child is not based on its parents' culture, but rather on the culture the child would enter given its physical makeup. (Lane 1997)

Indeed, in the case of racial minorities Lane is certainly correct in his assumption. The essence of bigotry is that it is aimed not at content, personality, character, talents or socialization but plainly and bluntly on one's external "identity badge" (Appiah 1996). Indeed Lane may also be right in his assumption that oral deaf people will be ascribed a deaf "badge" in the "hostile" world at large, whether they desire this or not (Lane 1997). From our (limited) experience with mainstreamed "oral" deaf adults, there certainly is some legitimacy to this position. We have never met an orally schooled, mainstreamed deaf individual that was not readily "categorizable" as being deaf. However great their achievements may be, the nature of their speech and restricted aural capacities reveals their deafness almost instantly. Lane is likely also correct in the assumption that the

magnitude of this negative badge can be significant, as the case of racial minorities shows (Lane 1997) This has led some to the perspective that we should not try to dissolve (since society has historically proven its unwillingness to do so) but rather embrace the "label" and redirect it into a positive collective identity or "life script", which furthermore can be politically positioned opposed to the negative badge and unjust treatment that ethnic minorities must endure in a society that refuses to revise its bigot attitude (West 1993)

> One form of healing of the self that those who have these [negative-ccw] identities participate in is learning to see these collective identities not as sources of limitation and insult but as a valuable part of what they centrally are (Appiah 1996, 98)

This implies that such constructed identities are meant to both provide "healing" to injured ethnic identities as well as allow political action that will invite society to lift its bigotry through, for example, affirmative action The most evident of this is perhaps the Black Power movement in the United States (West 1993) To realize this however requires to "exploit" the racial badge to some extent It requires that oppressed ethnic minorities visualize themselves as well as their struggle against bigotry In an analogy Deaf culture has embroidered on a similar theme with its construction of concepts such as "Deaf power" and "Deaf nation" (Wrigley 1996)

Indeed, it seems likely that deaf individuals who function in mainstream society must by definition live with certain liabilities because of their deafness Bigotry will likely play a role and will at least co-shape their experiences and self-narratives Yet are these self-narratives and self-images *necessarily* negative? And if they are, are we to consider them *so* negative that we ought to discourage deaf adults to seek identification in hearing society and self-segregate instead? Is the negativity experienced by the Deaf truly of the same order and magnitude as the experiences of racial minorities? We would argue that the self-narratives of mainstreamed deaf individuals need not be as gloomy as one may expect Besides continuously encountering problems and limitations, successfully mainstreamed deaf adults also seem to cherish their lives based on the "victory" of having "conquered" hearing society (Van Noort 1999) Still, one may reply, they a priori must have a self-image that is "injured" because of their limited ability to engage in hearing society Yet unless one upholds a rather extreme form of "emotional egalitarianism", in which *every* sense of "being different" or "being less" is thought of as undesirable, it does not necessarily follow that a Deaf culture path is better per se Any final appraisal depends on the specific nature of potential injury and gain, it seems, which requires a critical pragmatic evaluation of the two options

Disregarding the critique of extreme emotional egalitarianism, it appears that many non-disabled citizens actually experience being "different" or "less" at one time or another and maybe even lack a "distinctive identity", which perhaps makes such experiences a rather integrate part of life Still, we too would agree that there is a limit to

such a train-of-thought, hence do not rebut the core of the claim per se – certainly not in the case of deafness. All people have the right to some basic dignity and if it can be demonstrated that this is at stake, intervention may be warranted – if of course it has been shown that the specific intervention will be effective, and that it produces no unacceptable liabilities. One may respond by arguing that the high prevalence of psycho-emotional problems amongst deaf adults surely proves that we need not retreat to radical emotional egalitarianism to prove our point: surely these data establish that "basic dignity" *is* at stake here. Yet, as we have argued in chapter one, there is no consistent evidence that confirms that the increased risk of psycho-emotional problems amongst the deaf is mono-causally related to a stigmatizing experience in mainstream society, nor that mainstreamed deaf individuals are more at risk of developing a low self-esteem, nor that a low self-esteem is mono-causally related to psychological morbidity. As we have argued previously, there is little "hard-data" to go on in this context and navigating on our "intuition" can be rather deceptive.

So we have argued that the pragmatic premise of an inevitable "injured self" in the case of mainstreamed deaf adults has not been proven beyond doubt, though it remains a point of concern. Nonetheless if Lane's objections are primarily aimed at this risk however, it would seem that he is responding to what he believes to be the mediocre results of cochlear implantation. But what if there were a "perfect" treatment for deafness? What if the cochlear implant would succeed to provide deaf children access to spoken language skills? Surely it seems that the suggestion of an irrevocable ascription of a negative identity badge is unfounded in such a case. If Lane's arguments are primarily pragmatic, we would expect him to be positive about such a hypothetical case. Yet as we discussed, Lane *rejects* cochlear implants even in the hypothetical case of a "perfect implant" (Lane 1997). As such Lane's argument may be argued to be independent of the pragmatic or political best-interest of deaf children, and rather foundational in nature.

Acceptance as "foundational" tolerance & the case of racial minorities

The case of the "perfect implant" brings Lane's pragmatic assumption of the irrevocableness of a harmful "deaf badge" into question. But why is Lane upholding his resistance in the hypothetical case of a perfect implant? Is it merely a "strategic action" as we briefly discussed, counter-rhetoric to the appealing though misleading claims of "real-life" cochlear implantation – which is far from perfect - in the public media? Or does he truly feel that even a "perfect implant" would constitute a moral straying? In this paragraph we will investigate the latter possibility.

If we recall the structure of DC-ID , the latter conclusion may well have some merits. As we have argued, DC-ID essentializes deafness as a relevant "ethnic" trait, a trait that constitutes a specific "kind of person" "relating to sizable groups of people

sharing a common and distinctive racial, national, religious, linguistic or cultural heritage" that parents ought to respect (Appiah 1996; American Heritage Dictionary 1995; Wrigley 1996). As we have shown, Lane utilizes the argument of being born into an ecology - he speaks of a "birth right" - to support his argument (Lane 1997). Similar to the unconditional love demand, which also seems to rely on deafness as a relevant condition to a child's self, this argument appeals to parents' "attitude" or "moral character", be it not vis-à-vis their child's right to be loved unconditionally but rather to their right to have their cultural identity respected and upheld. Deviance from deaf ecology's prescriptions was as such depicted as a questionable moral attitude, of disrespect or intolerance even, rather independently of the potential pragmatic merits and liabilities of the "deviant" path.

> This book probes our commitment to tolerance by exploring how far we are ready to go in respecting the legitimacy of a linguistic and cultural minority that arises from a physical organization different from ours. (Lane 1992)

Since Lane appeals to this, a comparison to the case of racial minorities may perhaps enlighten our case. Lane and others have drawn parallels to the case of racial minorities and even though such a parallel may repulse us, we cannot simply disregard it: if cochlear implantation is to be considered an immoral act an sich, we have reached an end-point in our moral discussion.

From a rather shortsighted, a-historical and rather appalling pragmatic perspective it could be argued that we can, theoretically, overcome "racial" injustice by eliminating the "racial badge": if racial minorities would lack their racial stigma, racism would cease to exist. The peculiar thing about such a suggestion is both its uncontestable truth as well as its shocking immorality, and it seems as if Lane feels that this "instant judgment" should be adapted to the case of a "perfect" implant as well. Foundationalists may as such argue that a pragmatic approach to minority issues has some severe liabilities, namely that it can theoretically lead to such repulsive "pragmatic" suggestions – albeit a flawed form of pragmatism we would argue. Indeed, if we look at history these critics may be right: if we recall the historical infamous "busing-project" and intentional state-implemented segregation of Amerindian and Australian Aborigine children, foundationalists may be correct in their assumption that we need foundations to fence-off such brutal moral straying that stems – we will assume - from the desire to eliminate bigotry (Raphael 1998; Ruth 1989; Turner 1972; Blustein 1979). Many may thus feel that the moral inappropriateness of the above-mentioned suggestion is rather self-evident and severely improper, and that we may indeed have reached the end of where pragmatic reasoning should lead us.

Yet it may well be that this "self-evidence" ultimately stems from what Appiah wants to avoid: the perception of people with colored skin as a distinct "species" that ought to be preserved, which itself seems expressive of what he calls "racialism" and as

such seems a rather weak basis to prevent history to repeat itself. While foundationalism certainly has merits – foundationalism certainly works or works for now - we feel that illustrating and analyzing what could happen if we would consider changing the racial "badge" in itself can also be a strong and convincing moral repellent, without retreating to racialism or appealing to, potentially superficial, abomination. By doing so, the differences with the case of deafness also surface, which would not if we would limit ourselves to the sense of astonishing abhorrence described above.

Much more evidently than in the case of disability, the "social disadvantage" of a "racial badge" - that the above-mentioned pragmatist fallacy is trying to undo - stems from prejudice or racism *exclusively*. The same is true for gender and sexual preference. This implies that, for example in the context of the competition for jobs, African-American individuals will be at disadvantage even vis-à-vis *less* qualified white applicants, which demonstrates that the racial badge is one of color-prejudice and bigotry first and foremost. Needless to say, charging at the racial badge to dodge society's bigotry is a bizarre and immoral suggestion: it is clearly a "technical fix for social problems" for which the minority population is explicitly not to blame (Proctor 1988). If we would on the other hand get rid of bigotry and invest into the African-American community, much of the disproportional (to social-class) inequality would likely vaporize, and such a solution is much more appropriate from a moral perspective. That is not to say that social disadvantage would cease from our community, yet it would likely be reduced to some "normal range" that we accept in our pluriform society (which is not to say that we want to justify existing inequalities in Western societies).

For the disabled this argument applies as well, yet it is *not* confined to it: while discrimination and "purposeful unequal treatment" (US Public Law 101-336) have and continue to play a role in the social limitations that people with a disability face, "badges" and "labeling" are not the alpha-and-omega of the problems that a profoundly deaf individual encounters. In response to Wrigley we would suggest that deafness is also about "audiology" and not predominantly about "epistemology" (Wrigley 1996). Even in a non-stigmatizing society, a deaf person will still be unable to perform certain central tasks unhampered and will still experience hurdles in terms of finding membership to "the moral unity of humanity", even though his or her situation would likely be improved over what it is today.

Now one may respond by questioning our suggestions: the above-mentioned "limitations" that a deaf individual will continue to experience in a "non-bigot" society may be argued to demonstrate that bigotry or at least "injustice" does continue to play a role, and that we as such should demand that society accommodates for these limitations as well. Lane draws a parallel to the case of short people by stating that a deaf child is "a healthy child like a healthy short child" (Foreman 2001). We feel that this parallel does not convince: again, beyond bigotry there is *nothing* that limits a healthy short child access to opportunities. Therefore, if limitations are experienced nonetheless, bigotry is a

likely culprit and would legitimate a moral renunciation of such occurrences. Yet, Lane may suggest more in his parallel to short children. He may suggest that, like short stature, we ought to consider deaf children to fall within the "normal range" of the humankind, and as such need not attempt to alter their state. Yet this train-of-thought is particularly unattractive to deaf children, we feel. If we accept short people to fall within the "normal range" of the humankind, there is also little ground to demand socio-political compassion towards them it seems – unless we can make a case that bigotry or injustice are at stake. Yet, surely Lane does seek special measures for the deaf. So how are we to correlate the two cases in this context? It appears that if we want to uphold the paragon of short people without sacrificing such "special measures", we must show that bigotry or injustice are at stake nonetheless.

One may argue that short people, like the deaf, *do* actually experience limitations in terms of their access to certain opportunities: a short individual will be at disadvantage if he or she wishes to become, let's say, a professional basketball player. One may reason that such limitations are the consequence of "bigotry" or "unfairness" and that society should respond correspondingly, for example by lowering the basket-height in the NBA (Gutmann 1996a). We would question this proposition however. Bigotry seems a false accusation, since the limited access to the goals of becoming a professional basketball player does not result from a prejudiced-based unequal treatment in spite of one's talents: short people are not at disadvantage because of prejudice but rather because of a real disadvantage due to their height. This makes their case different from that of talented African-Americans who lose jobs to less-talented white applicants, and makes a bigotry-based appeal rather inappropriate.

Still, one may continue to argue that the experienced disadvantage of short people in competing for an NBA position must surely be considered as at least "unfair" (Gutmann 1996a). In this context, Gutmann makes a distinction between "basic" opportunities and "non-basic" opportunities, which are treated within more or less separate moral spaces. Basic opportunities are items such as healthcare, an income and a job. Gutmann considers it our political duty to make these opportunities available to all citizens, regardless of their talents. This position stems from the belief that all citizens have the right to "a decent life according to the current standards of the society in question" (Gutmann 1996a). It is likely aimed to provide a safety-rope for those individuals whose talent to compete for basic goods, falls below a certain threshold: falls below what we may consider the "normal range" or variance of individual talent that we "accept" in our society. It seems to us that the case of the short individual that aspires a NBA position does not qualify as a case of "basic" opportunities. As such one cannot claim such an aspiration as a "right". One could expand the basic opportunities to the "needs" that people have, which would perhaps qualify the desire to play professional basketball as "basic" and the denial thereof as "bigot" or at least "unfair", yet as Gutmann argues the problem with such a view is that "needs are omnivorous". The belief that public policy should be based on individual (identity) "needs" has led some to claim

that "even citizens who would rather surf all day off Malibu are entitled to welfare" (Van Parijs 1991).

Non-basic opportunities are the goods that citizens may seek *beyond* the basics, in their quest for the "good life". Gutmann discusses these aspirations within the moral space of "fair opportunity". The question thus becomes if unequal access to the NBA constitutes "unfair" treatment, which is ultimately a question that leads us to a rather extensive political-philosophical debate between liberals - who advocate "fair competition" - and egalitarians - who sometimes favor preferential treatment of disadvantaged people. Yet, even most egalitarian thinkers, advocate preferential treatment *because* society has failed to fulfill its fundamental tasks to safeguard basic opportunities for all its citizens, rather than radically aiming at the resolution of all forms of inequality due to the range of talents that characterize people – barring the most extreme egalitarians (Gutmann 1996a). They hence call for preferential treatment because some inequalities to compete for non-basic goods are the direct result of our failure as a society to comply with our moral duty to provide all our citizens with basic opportunities such as a decent education. As such it seems that the case of short people that aspire a career as a professional basketball player does not fit this objective, and rather constitutes a much more "radical" form of egalitarianism.

We would thus argue that the disadvantage experienced by short people falls within the "normal range" of variance in "talent" or "native ability" – which are the result of a "natural lottery" - in competing for "non-basic" goods, rather than being the result of unfairness per se (Gutmann 1987): besides short people many (if not most) people of all creed will be unable to realize such a goal because of limited physical skills or talents. To claim equal access to a "non-basic good" to which one has limited access based on one's limited talents to compete, seems unreasonable if society is not to blame in terms of "bigotry" or "injustice" in not providing basic opportunities. This implies, we feel, that it is questionable if it supports the case of lowering the basket-height from a moral perspective. It thus seems that aiming to be a professional basketball player falls beyond the fundamental "right" to equality that we can claim based on a notion of "bigotry", "injustice" or "unfairness".

As such we conclude that the paragon of short people is rather inappropriate to the case of deaf people. If we equate the problems that deaf people encounter in our society to those experienced by short people, we not only devaluate the case of deafness but also damage deaf people's interests, since it would leave them with little to claim really. Yet, contrary to the case of short people, even though "bigotry" is not at stake here, access to "basic opportunities" is as the direct result of the handicap. As we argued, even in a non-bigot society deaf people are likely to miss out, even in terms of their access to basic opportunities. As such, it is only *fair* that we provide the deaf with adequate access to such opportunities – be it not based on our culpability as a bigot culture, but rather our duty as a civil society. The fact that – contrary to racism – no one is to blame really,

perhaps explains why some have refrained from placing the moral burden with society as we explicitly would in the case of racial minorities, but have rather focused on society's "collective responsibility" or "solidarity", which is also expressed in the American Disability Act (Appiah 1996, Reinders 2000) The fact that no one is to blame implies that placing the blame with the disabled unilaterally is an unjust solution the physical limitations are "characteristics that are beyond the control of such individuals" (US Public Law 101-336, Gutmann 1996a) Indeed Lane also seems to appeal to this notion

> Our society is sufficiently rich and enlightened that we are prepared to sympathize with marginal people who endorse our norms but, for reasons beyond their control, cannot live up to them (Lane 1992)

We should not demand that the disabled unilaterally deliver the change needed to improve their access to basic opportunities, since this would suggest that they are to blame - though we should be careful not to fall victim of a pitiable view on disability in doing so ("we should not demand *anything* from disabled people because they are pitiable and sad enough as they are") As a people who cherish fairness and solidarity we can provide the means to implement changes that allow the disadvantaged to engage in the "normal range" of basic opportunities and perhaps beyond Facilitating access to public buildings and transportation ("civic access") and guaranteeing a basic income are such changes, providing a decent education and Sign translators for deaf people are as well Lowering the height of the basket to allow short people to become professional basketball players is a questionable claim however, even though – as we argued - some extreme egalitarians may not agree

Yet the fact that no one is to blame *also* seems to imply that a disabled person cannot necessarily unilaterally put a claim on society's duty to provide his or her access to opportunities It is this position that deaf lawyer Tucker critically addresses in her analysis of "elective disability" Tucker questions the unrestricted legitimacy of disabled people to reject treatments that can improve their access to opportunities while continuing to make claims on society to provide these opportunities (Tucker 1998) A similar problem also surfaces in the lively "welfare versus workfare" discussion, in the context of people who refuse to work yet do continue to make a demand on society to provide basic opportunities (Gutmann 1996a) It seems that those who advocate welfare – the right to an income regardless of the willingness to work – reason that there will always be people who fail to get a job in spite of their efforts, and that these well-disposed people must be protected Advocates of workfare – the right of income is linked to making an effort to find work - on the other hand likely feed on the danger that some people will unreasonably refrain from work It thus seems that the intention of the individual, his or her "reasonability", is rather central here As such it seems that if a disabled person can make a contribution to his or her access to opportunities and if such an effort is perceived as "reasonable", it is reasonable that he or she does so

Yet there is more to the comparison of the case of cochlear implantation to racial minorities Moreover, and this is a crucial issue we feel, most black children are born and socialized in a African-American family through a rather natural and fully constitutional process in our society adults of any color, social-class or worldview have a right to bear children and raise them to their preferences, unless it is proven that they disadvantage their children beyond some "normal range" (a thorny concept) of accepted intra-cultural variability - we will elaborate on this further in the next section Indeed, in contemporary Western society ecology is shaped by the biological family foremost - through social practice of an almost constitutional form (Parker 1997, Blustein 1979, Mnookin 1979) Abrams speaks of a family's "liberty of non-interference" which is actually supported by jurisprudence (Abrams 1979, Uviller 1979) By this paradigm gross cultural paternalism is averted it protects those with resources and preferences beyond the mainstream - such as religious minorities like the Amish, socio-economic minorities and linguistic minorities such as Deaf parents with hearing children – from infringement "Equalizing life chances" through elimination of the racial badge is thus not only immoral because it seeks a solution from those victimized, this constitutional right also limits it as Gutmann underscores

> Why should a deliberative perspective reject an interpretation of fair opportunity as a demand for equalizing life chances? One reason is implicit in the basic liberty principle The freedom to raise children is a basic liberty, and even though it is far from unlimited, this freedom precludes the kind of government intervention that would be necessary to equalize life chances (Gutmann 1996a, 310)

For parents of African-American children, having the physical trait of a black skin in a prejudiced society will likely have co-shaped their identity and as such will likely co-determine the life-story that they raise their children with (Appiah 1996) From this perspective too, changing racial badge strikes as a bizarre proposition as it will insult parents' dignity, harm their need for "narrative unity", create a breach between parent and child and painfully introduce identity-politics into the private home, which is unlikely to benefit parent nor child (Appiah 1996) Moreover it is rather questionable if or to what degree such action would *really* improve African-American's interests, which we suppose is at stake here rather than overt racism, since it may simply replace racial bigotry with socio-economical bigotry or "classism" As such it seems that the moral liabilities outweigh the assumed benefits by far

The "perfect" cochlear implant would have the opposite effect it would restore rather than injure parents' narrative cohesiveness Peculiar of the way in which "belonging" is being constructed by Lane in the case of deaf children, is that it does not conform to the common constellation of criteria such as "soil", "blood", "language" and "tradition" (Derrida 1996) In most instances soil, blood, language and tradition will form a harmonious entity The place where a child is born will likely determine the tradition and language in which he or she is raised and all of these factors will likely be shared by their natural parents The *être-chez-nous* of which Derrida speaks in the context of

identity, or where one is "at home"("casa"), is commonly the *physical* home formed by the natural family (Derrida 1996) Yet in the case of deaf children, Lane suggests that a deep division runs through the former and the latter (Lane 1997) An essentialist framing of deafness as a cultural issue has several emotional consequences for parents, the most direct of which is that parents are potentially made to feel that they have given birth to a child, yet they cannot experience the kind of symbiosis they desire this child is not just "different" like all children are, but different in an *essential* way This implies that by placing emphasis on culture, Deaf culturalists implicitly confront parents with the image of a child that is not really theirs, which is "distinct" from his or her parents As we have shown, this framing stirred upset in many parents, which can be readily understood from our discussion of racial minorities Perhaps the contest over belonging can also be localized in the language debate Deaf culturalist linguists consider Sign language the "mother language" of a deaf child Still, over 90% of deaf infants have parents who communicate in an oral modality rather than sign, hence if one departs from the *intuitive* meaning of the concept rather than the theoretical-linguistic meaning of it, it seems awkward to consider Sign the "mother language" of deaf children it seems to at least suggest a dispute over motherhood and belonging (Meadow 1980)

While the immoral consequences in the context of racial minorities are not at stake in the case of the "perfect implant", and such an implant would sooner restore than insult parental rights and dignity, and a "perfect implant" would much more likely improve deaf children's interests, the dignity and narrative cohesiveness of the adult Deaf population *is* at stake here and Lane has a strong and legitimate point when he expresses concern over this issue These people share a segregated and isolated biography and share a language, which most likely co-determines their social identity To them, the case of the "perfect implant" may certainly be a source of narrative incohesiveness and agony, be it not within the proximity of the private family sphere Yet while this ought to at least prompt us to take the fate of the adult Deaf population seriously, we do not directly see how this would lead to a renunciation of the perfect cochlear implant Returning to the paragon of the Molokai Leper community that we discussed in the previous chapter, such a position would lead to continuous segregation of "new" Leper patients in spite of the fact that we now know that this is a scientific straying, even though it seems unlikely that members of the Leper community perceived themselves as an ethnic group as strongly as the Deaf do

We conclude that a parallel of the "perfect implant" to the case of racial minorities is not sound, at least not uncomplicatedly Surely deaf history has its own appalling examples of where an one-sided and shortsighted pragmatic focus on "best-interest" can lead to, as the case of Bell's crusade against Sign language and Deaf group-formation illustrates, yet we do not see how the case of the "perfect implant" stems from this directly, unless the motive behind both Bell's thought as well as the notion of a perfect implant would be pure bigotry, which we feel is unlikely (Wrigley 1996) Still it seems that implant teams were shocked and confused by the parallel that Lane has drawn to the

case of ethnic minorities, as many implant team members tumbled-over-each-other to quickly comfort us with the message that cochlear implantation does not fit the image of "identity surgery" since implanted children "remain deaf" While this may be true for the actual implant reality, it does not answer Lane's hypothetical critique regarding the "perfect" implant It seems to us that the confusion stirred by the equation of cochlear implantation to "identity surgery" works through its implicit, and sometimes explicit, appeal to the case of racial minorities and the general foundational awe that this instills Yet there may be more to this issue, there may be emotions involved that are only tangentially related to the concrete issue of racial minorities One possibility we touched upon previously ("racialism") yet questioned critically by drawing a parallel to racial minorities we are made to feel that we are indeed blameworthy of altering a specific "species" if we consider cochlear implantation Another possibility refers to popular modern views on "authenticity" as we will discuss in the next paragraph

Acceptance as "foundational" tolerance & the existential need for "authenticity"

The concept of "identity" has become a central cultural notion - perhaps most passionately in North American culture - that is only tangentially related to the social injustice of racism in its day-to-day application The need to "fit each individual story into a larger (foundational) narrative" seems to have become rather important to us (Appiah 1996) This larger story can be provided by collective identities, but it can also appeal to individual authenticity

> Authenticity speaks of the real self buried in there, the self one has to dig out and express (Appiah 1996, 96)

A liberal view on identity would, it seems, mostly safeguard the means to unrestricted "authentic" identity formation it would make sure that society allows an individual the moral space to "create" his or her identity, by tearing down restrictive or conservative institutions and social prejudice against specific expression forms This thus includes a struggle against social prejudice aimed at individual expression forms so people can freely identify with them if they please, yet it paradoxically also implies skepticism against institutions that restrict identity-formation through the promotion of coercive or fixed identity-scripts – since these will limit people's freedom to self-identify This is precisely where authors such as Appiah disagree with identity meta-narratives, even in the case of ethnic minorities it may lead to the creation of a coherent collective and coercive ethnic identity that prescribes precisely how "a proper person of that kind behaves" (Appiah 1996) For liberals, the fundamental right thus lies with the *process* and not the outcome per se people should be free from oppression to shape their identity The outcome is secondary to this and is, moreover, not considered as "fixed" per se Expressive of this view is Appiah's advocacy of "fractured identities", "identity play"

and "irony": this seems to be his answer to the potential paradox that characterizes the liberal view on identity (Appiah 1996). As such the introduction of a *specific* identity into the socio-political arena does not follow logically from a liberal perspective on identity. While creating the moral space for specific identity expression to be available is, demanding that specific identities are "recognized" politically is not necessarily a position that liberal thinkers such as Appiah would subscribe to, at least not conceptually (pragmatically Appiah does recognize specific strategic advantages).

Notwithstanding our suggestion that from a liberal perspective, specific identities have limited (conceptual) value in the political arena, there seems to be a rise of political identity claims, as may be illustrated by Van Parijs' theoretical advocacy of Malibu surfers that we discussed before (Van Parijs 1991). Van Parijs perceives his advocacy as "liberal", and indeed if we focus on his advocacy of the freedom of self-expression his ideas may very well be perceived as liberal. Yet Van Parijs' view does draw specific identities into the political arena, since he feels that Malibu surfers can legitimately put their claims on society, which seems like an advocacy of rather fixed identities. The above-cited example of the idea of an "authentic nugget of selfhood" – people can only "become" who they intrinsically "are" - also seems to represent this perspective. If people indeed have some fixed and inalterable "authentic nugget of selfhood" it appears reasonable that society recognizes this and refrains from demanding a change of identity, even if the specific nature of that identity clashes with common culture.

Focusing mostly on "outcome" by defending people's "right" to specific identity expressions without addressing the negative liabilities that this can have on people's liberal freedom to self-create their identity, thus seems symptomatic of a specific political view. This has led some to the critique that modern identity-politics has strayed away too far from the case of overt bigotry that ignited it, and has become victim of cultural "narcissism" (Lasch 1979). Rather than embracing the challenge of creating ourselves, we retreat from this postmodern "freedom" by embracing the notion of a fixed meta-narrative that covers our existence (Fromm 1994). Furthermore, if our fixed-selves result in social inequality, as it likely would in the case of Malibu surfers, we make a political claim to evade this rather than "adjusting" to the standards of common culture. Toulmin, Rorty and Appiah all warn that retreating to a collective identity potentially represents "laziness", as the creative labor of defining a self in our modern secularized society is dodged rather than confronted: people insist on "respect" through "labelism" rather than gaining respect through authentic effort (Roovers 1998; Rorty 1998b; Appiah 1996).

As we argued, it seems that identity-politics originate in bigotry and the perceived need to call this a halt, and apparently got "lost" somewhere or another. It may be that the need or "strategic" advantage of a foundational perspective on identity has caused the "foundation" itself to lead a life-of-its own, hence explaining its rather radical application beyond the domain of overt social injustice (Gutmann 1996a). The notion that our

identity is "buried" somewhere can be perceived as dismissing critique on identity as a self-constructed "lazy" or "narcissist" notion, that is of questionable importance in the political arena and hence weakens the political case After all, the constructiveness of "identity" is also immediately visible in the case of some ethnic groups

However "confusion" or "straying" is not the only possible explanation Some may genuinely feel that we actually have quasi-biological fixed "identities", or at least have an existential *need* for such identities Not recognizing our "created" or "discovered" identity may be argued to lead to an undesirable "negative sense of self" Therefore it could be argued that such a "politics of identity" represents an "emotional egalitarianism" that we also discussed in terms of the anticipated "injured" selves of mainstreamed deaf adults it potentially represents the view that all people have a right to equal public and political dignity The popularization and politicizing of the concept of "self-esteem" fits into this view and potentially reveals that the moral basis of "emotional egalitarianism" is much more widespread in common (American) culture than the political-philosophical debate would suggest While we cannot go into more detail in discussing this highly complex political discussion, it does seem that – at least in the political-philosophical arena - the valuing and politicizing of "fixed" identities feeds on the concrete socio-political inequality that certain minorities must endure in our society In the case of "emotional egalitarianism" its advocacy has expanded this to a general and very broad political view that includes everyone really (Gutmann 1996a) We feel that in the political-philosophical arena, "identity" as a foundational concept is valuable only in strict reference to the political context in which it originates, unless one adheres to "emotional egalitarianism" Gutmann has verbalized this point eloquently

> Many of the lists of "oppressed groups" in need of special representation turn out to include the vast majority of Americans [ ] To guard against balkanizing citizens into so many distinct groups, any form of group representation should be carefully tailored to the context [ ] Group representation schemes that are designed primarily for black Americans may be justified even if group representation for every disadvantaged group would be impracticable [ ] Group representation is not itself a moral end, but electoral schemes that satisfy these conditions may be justifiable means to better representation, especially in a society that is still plagued with racism and other forms of discrimination against disadvantaged minorities (Gutmann 1996a, 154)

As we discussed, indeed some minorities have been treated with bigotry and severe indignity and a call for recognition can "heal" this pain, as well as present a powerful and legitimate political arena to correct the resultant inequality As we also argued, to understand the legitimacy of this claim does *not* require that we create a moral foundation of "fixed" identities it stems rather logically from an analysis of the political context

This brings us back to what we discussed in the previous section We can choose the "strategy" of foundationalism to reach our goals, but should be aware of the *origin* of

our action and hence be aware that foundationalism does not become an ideology of its own – an ideology that legitimates itself rather than gaining its legitimacy from the strategic plan to correct socio-political immorality. As such we feel that if such socio-political immoral events do not comprise, or do not comprise fully, the reality of groups - such as deaf children in the case of a "perfect implant" - to allow the moral conclusions to remain nonetheless is questionable, unless we explicitly subscribe to the radical (emotional-) egalitarian political view that underlies it. The confusion that the verdict of "identity surgery" invokes is unlikely a result of our political-philosophical support of such an egalitarian view per se, but rather stems from a cultural popularization of this philosophy. In these times of "self-esteem", many of us may self-identify with the global and symbolic outlines of the cochlear implantation debate. Yet the usability and appropriateness of this latter popularization in a concrete and complex ethical case such as cochlear implantation, is questionable we feel. It does allow us an understanding of the emotions that a specific case may stir, but is a questionable guide in seeking a fair solution.

Acceptance: "foundational" tolerance or "strategic" pragmatism?

We have illustrated how the case of racial minorities does not fit the case of the disabled uncomplicatedly. Yet some may argue, as we have shown in the previous paragraph, that this does not matter really, since what is at stake is that disabled people have a "unique" and "authentic" identity that we should not make any demands on as a civilized society. We argued that this latter perspective is of questionable significance if it distances itself from the political-social reality from which it originates. Still, it is a culturally popular position. Yet it remained unclear what underpins this latter position from a political-philosophical perspective. Does this view perhaps lack a political-philosophical underpinning altogether, and is it as such little more than a projection of popular cultural values onto a concrete ethical case? Though this cannot be excluded, we feel that this is highly unlikely. Is it because those who have advocated foundational identities devote themselves to "emotional egalitarianism"? While this possibility is much more likely than our first suggestion, we still feel that it is an insufficient explanation. Another alternative explanation is that identity is though of as a "biological" entity, a train-of-thought that Appiah has critically coined "cultural geneticism"(Appiah 1996). This view overlaps with our discussion of "fixed" identities in the previous paragraph, yet grounds this even more fundamentally. It dodges a constructivist view on identity, which does has the advantage that the critique of "laziness" and "narcissism" are also averted.

Appiah illustrates that "cultural geneticism" has a long history and has served a variety of, mostly political, purposes. Central to "cultural geneticism" is the concept of "soul", which best captures the link between identity and a biological sense of inevitability. The notion of "soul" represents an essentialist identity notion in which people represent a "stable core of experience" (Parker 1997; Appiah 1996). 18th century

philosopher Herder claimed that all nations had such a "unique" way-of-being, that could not be interchanged (Finkielkraut 1995). Herder's motives were highly political however. In part because a distinctive German nation state was lacking in his times, Herder argued that *Sprachgeist* or "spirit of the language", defined a people as a distinct political unity or "Volk" (Appiah 1996). The issue of such a unique spiritual identity has remained of influence throughout the twentieth century, again mostly in the political context of oppressed people (Du Bois 1903). Much similar to Herder others have also assumed that language gives rise to unique identities, identities that share "moral and literary endowments" (Appiah 1996).It seems that the notion of "soul" is also implicit to Lane and Alden's argument. It seems that both assume that being deaf in itself somehow establishes such a unique spiritual substance rather irreversibly. As such, Lane seems to argue that having the physical trait of deafness itself is somehow sufficient to prove the immorality of a "perfect" implant and the inviolability of Deaf culture as the identification-path for deaf children. Deafness is as such postulated as being considerably more than "not-hearing", but rather defined as an irrevocable identity-determining trait, which makes cochlear implantation "identity surgery" and the intention behind it "ethnocide" (Foreman 2001). Given this portrayal the shock and confusion by parents and implant teams is not hard to understand. Yet let us scrutinize this thought more profoundly.

Lane assumes that there is something more profound about deafness, something beyond identity-socialization, which makes deaf people into a specific "kind of person". The visual orientation and unique visual language of deaf people are considered paramount in this respect: Lane repeatedly speaks about deaf people as "visual people" which seems to suggest that we are dealing with a distinctive "species" here (Appiah 1996). Much like Herder, the unique language of Deaf people is also perceived of as paramount.

> Research indicates that language powerfully influences attitudes, behavior, and perceptions. To ignore this factor [...] would be cultural suicide. (Maggio, in: Alden 2001)

This unique spiritual substance or "essence" is depicted as the hallmark of the sense of "belonging" and "solidarity", which in turn are considered of almost biological vitality to human life (Appiah 1996).

> As soon as Clerc caught sight of this [deaf children having lunch-ccw], his face got a lively expression. He was moved just like a traveler with a sense for art would be if he would meet a group of countrymen somewhere abroad. (Kyle 1990 - translation ccw)

Lane and Alden do not stand alone in their view. As Skolnick and Appiah observe, in recent years there has been a growing development towards a "new biologism" or "cultural geneticism" in which physical attributes are assumed imperative in terms of identity and cultural heritage (Skolnick 1998; Appiah 1996). From this perspective, Appiah argues that the new "cultural geneticists" feel that "Jazz belongs to a black

person who knows nothing about it more fully or naturally than it does to a white jazzman" (Appiah 1996). It is this foundation that co-explains for example the position of anti-adoptionists in the United States: being born black is in itself considered reason enough to insist on culturalization in African-American culture (Lane 1997).

> On this view, you earn rights to culture that is marked with the mark of your race – or your nation – simply by having a racial identity For the old racialist, as we saw, your racial character was something that came with your essence, this new view recognizes that race does not bring culture, and generously offers, by the wave of a wand, the correct Nature's omission (Appiah 1996, 90)

Yet as we said, Appiah as well as others have criticized this view on identity - at least beyond the context of oppressed minorities - because spiritual "identity" substance gains almost the same coerciveness as the much older "biological" conceptions of "essence" and "difference" did (Appiah 1996) West feels that claims to racial authenticity "discourages moral reasoning", a diagnosis which complies to our previously mentioned comment that Lane's axiom of a fixed Deaf identity calls a halt to further moral inquiry (West 1993). Appiah is skeptical even in the case of oppressed minorities, though he acknowledges that a fixed view on identity and cultural heritage may be necessary from a strategic vantage point. Furthermore, he feels that there is some legitimacy to this axiom in the case of adults with an identity that has already been formed, an issue he coins as the "ethics of authenticity". To demand from such adults that they refrain from identification seems unnecessarily unkind, unfair to the history that has shaped their identity, inequitable to the strategic and affective benefits from such a discourse and unreasonable in terms of their need for "narrative unity" (Appiah 1996). It is this ambivalent position vis-à-vis minority identities that also shapes the case of requesting change from the disabled, if such change would better their access to opportunities – to which we referred previously in the context of Tucker's argument against "elective disability". More so than in the case of racial minorities – since in the case of the disabled, society is not as blameworthy - it seems legitimate to ask the disabled to make a contribution to improve their situation if possible. We argued that the acceptability of such a project likely depends on its "reasonability": narrative cohesiveness seems an important ingredient of what we would consider reasonable This is, we feel, an issue that Tucker has overlooked somewhat in her critique on elective disability (Tucker 1998).

We recall that the idea of a foundational identity originates mostly from authors that write in reference to a *specific* context of socio-political injustice Though the concept of "soul" originates in 18th century Germany, it has been applied most widely in the case of the African-American minority. Though the concept of "soul" has become widely popularized since - cross-referring to Van Parijs we note that the concept of "soul surfing" is very popular today – this grounding in genuine socio-political injustice seems to suggest that we should perceive the concept in this specific context As such the strategic advantage of "cultural geneticism" seems paramount here.

> Some exclusiveness in representation may be desirable if it is the only way that the long-standing grievances of black citizens can be effectively addressed But as a permanent mode of representation, it is likely further to divide citizens and discourage deliberation (Gutmann 1996a, 153)

As such we would side with Appiah and Gutmann on this point, and underscore that foundationalism of this kind has distinct liabilities yet might prove effective to the political case of oppressed minorities nonetheless Anti-adoptionalists for example, likely want to avert a repetition of the busing-project they want to call a halt to those that unjustly feel that we can solve our socio-political problems by "handing-over" minority children to majority culture They actually want to "discourage moral reasoning" – that West and Gutmann depict - since moral reasoning has historically proven to be potentially fallible If soul and identity are framed as "necessities" of an almost biological nature, something people on the one hand "cannot help" having and on the other have a fundamental right of having, any intervention becomes a questionable act Clearly this is a powerful discourse that likely co-explains why the concepts of "soul" and "identity" have risen so prominently in multi-cultural debates Indeed it seems that much of the confusion stems from the fact that "foundationalists" create their foundations vis-à-vis a concrete political reality, and not for the sake of foundationalism per se They are in fact pragmatists, yet feel that a foundational approach is ultimately much more effective than any pragmatic strategy is likely to be Appiah feels that it makes little sense to assume that "race" as some kind of profoundly routed authentic construct really exists, rather he views race as a "political morality" (Appiah 1996) West joins Appiah in this conviction and feels that race "is a political and ethical construct" ultimately, something that is concealed by those appealing to the issue of authenticity (West 1993) As West further argues, the rise of this theme corresponds to a specific view on minority politics

> Escalating black nationalist sentiments – the notion that America's will to racial justice is weak and therefore black people must close ranks for survival in a hostile country – rests principally upon claims to racial authenticity (West 1993, 24)

The "political case" is thus central in understanding a foundational identity discourse, beyond this the legitimacy becomes rather questionable, unless one prescribes to a specific political-philosophical view that we have labeled "emotional egalitarianism" If we lose touch with the concrete political case however, foundationalism may actually come to lead a life-of-its-own and may harm rather than benefit the political case This implies that we should not forget for what reasons we are "tolerating" a foundational perspective on identity and should monitor if our objectives are being realized Thus, multicultural debates do originate in concrete socio-economic or political realities rather than being founded on an abstract concept such as "soul" in itself Appiah speaks of the "irony" of foundational approaches to minority issues in this context to illustrate this point, to illustrate that foundational views on identity are not motives in themselves but

are rather intended to resolve the vulgar socio-cultural-economical exclusion of racial minorities in a bigot society.

> If, in understanding myself as African-American, I see myself as resisting white norms, mainstream American conventions, the racism (and, perhaps, the materialism or the individualism) of "white culture", why would I at the same time seek recognition from these white others? (Appiah 1998, 94)

As Appiah's excerpt also illustrates, if a foundational identity politics *does* come to lead a life-in-itself, the original objective may even be overrun. If battling "stigma" or "recognizing otherness" becomes the *leitmotiv*, a foundational approach is at risk of turning against its original premises, though some political schools (that do not seek a "moral unity of humanity") may contest this (Rorty 1998b; Rorty 1998a; Appiah 1996; Gutmann 1996b; Taylor 1994a). As such we should continue to monitor the interests of minorities and be aware of the potential of the powerful "soul" argument to overrun these interests (Appiah 1994, 1996; Rorty 1998b).

> To take pride in being black or gay is an entirely reasonable response to the sadistic humiliation to which one has been subjected. But insofar as this pride prevents someone from also taking pride in being an American citizen, from thinking of his or her country as capable of reform, or from being able to join with straights or whites in reformist initiatives, it is a political disaster. (Rorty 1998b, 100)

In the American educational context, an example of this is the controversy that has risen over the issue of "acting white" (Cook 1997). Some African-American students supposedly view academic achievement, a foundation of social progress in mainstream society, negatively because it is identified as "acting white", hence causing a moral gridlock between our desires to respect ethnic identities – from the vantage point of moral responsibility (racial minorities are not the culprit of social inequality), the "ethics of authenticity" (we cannot limitlessly demand that people with shaped identities transform themselves), strategic potential and the need for "healing" - as well as improve their socio-economical situation. In the case of public policy, this situation exacerbates into the question if such "identities" can justifiably claim access to basic opportunities, as we discussed before (Gutmann 1996a). Toulmin would perhaps respond that this is the result of cultural relativism, in which each and every claim to authenticity is considered sacred, even those of the Malibu surfer (Roovers 1998). Indeed there seems to be a sliding-slope between a legitimate "ethics of authenticity" and the much more contested "emotional egalitarianism". On a somewhat similar line Appiah feels that it is undesirable that identities are scripted this tightly and that we should avoid identity to become an overly "obsessive" focus in our deliberation of minority politics (Appiah 1998). Narrative discontinuity is, it seems, ultimately unavoidable if one aims to vaporize bigotry and social injustice – thus not *every* form of discontinuity should be perceived of as an immoral act. Unschooled and unemployed minority parents with identities to match will experience some degree of narrative discontinuity if their children enroll in a

predominantly white Ivy League college, yet it seems questionable if we should therefore refrain from creating such opportunities for these children.

Hence "cultural geneticism" risks losing-touch with its original aims, which can cause the original aims to be injured rather than advanced. Indeed Lane as well as others have suggested that this may be the case in the context of deafness (Tucker 1998; Bertling 1994).

> Speech and thinking like a hearing person are negatively valued in Deaf culture. Deaf people who adopt hearing values and look down on other deaf people are regarded as traitors. (Lane 1992)

Wrigley claims something similar, and clearly brings an analogy to the "acting white" paragon to the forefront:

> For a Deaf person, "very hard-of-hearing" means someone who is trying very much to be like a hearing person, even though he or she may be quite deaf. As a pejorative, the phrase describes those deeply invested in denying their deafness or in attempting to "pass" as hearing. (Wrigley 1996, 15)

Cochlear implantation may indeed be equated to "identity surgery", but it seems not in the sense of altering "biological" essence but rather through changing a person's likely social identification path: in the case of a "perfect" cochlear implant it seems unlikely indeed that an implanted child would come to self-identify as Deaf. The political context is different from that of racial minorities as we have shown and most of the moral liabilities that do occur in the case of the latter do not occur in the case of a "perfect" implant, the only exception being the assault that implants cause on the narrative continuity of Deaf adults. The question hence becomes really if we feel that such objections are credible enough and of enough weight to outbalance the benefit that a "perfect implant" would yield for a deaf child. We feel that this is at least questionable and as such feel that a foundational approach should not a priori override a closer look at what cochlear implantation can yield in terms of a deaf child's best-interest. In the hypothetical case of a "perfect" implant, the choice for such an implant appears at least a "reasonable" choice, since many of the liabilities and moral constraints that we discussed in the case of racial minorities do not occur, or do not occur as violently. A "perfect" implant would vastly increase a child's access to basic opportunities, likely much more effectively than "solidarity" on society's side ever could, while it would not necessarily imply that we seek our solution in the wrong "moral compartment" so to say, since society is not to blame in the way that it is in the case of bigotry. Moreover, the case of a "perfect" implant would not make unreasonable demands on individuals nor their families in terms of narrative cohesiveness. It does not necessarily follow from this however, that a "perfect" implant would be the *only* morally justifiable action vis-à-vis pre-lingually deaf children of hearing parents. As we will illustrate in the next section,

the best-interest approach to proxy decisions is too nuanced to allow such a conclusion too hastily.

Conclusions

In this section we have investigated the concept of tolerance within its distinct discursive contexts. One context that materialized as particularly important was the context of Deaf culture. As Lane's objection to the "perfect" implant reveals, this is the most foundational critique against cochlear implantation. We investigated the different trains-of-thought that could lead to the rejection of a "perfect" implant. By doing so we drew parallels to the case of racial minorities and the debate that this issue has stirred, mostly in the United States. We have tried to illustrate that there are distinct differences with the case of racial minorities, even though some political schools may not agree with this. We have described the surfacing of the concept of "soul" as an essentialist identity that originates from the case of racial identities, yet side with Appiah that this is a political-strategical rather than a foundational concept and that the value of the concept lies with its power in the political arena. We hence suggested that the foundational concept of identity has a political-strategic function first and foremost and refers to a *specific* political reality, and that we should be careful not to forget this function.

From this material we conclude that the concept of a foundational Deaf identity is questionable. Rather, like in the case of racial identities, it serves a strategic purpose foremost. However, this strategic goal is neglected if one insists that even the case of a "perfect" implant is to be rejected. Now one may reason that Lane must disagree with us on this point, or alternatively that he has fallen victim to an error of thought - or that we did. While all three options are possible, we think a fourth option should be considered: Lane may also oppose the case of a perfect implant as a pragmatic strategy that is very much aimed at the reality of cochlear implantation, which is certainly not perfect. Lane may reason that the promise that the issue of cochlear implantation radiates may have undesirable consequences. He may reason that the appeal that implants have, may once again lead to one-sided pragmatic reasoning that may blind us to the genuine limitations of the implant, and close our minds to the true merits of Deaf culture. As such unbounded hope fueled by cochlear implantation, can be the prelude of a new era of shortsighted policies in the education of deaf children. Though Lane has also made these convictions explicit, as we will discuss in the final chapter, he apparently feels that a foundational approach will be more successful in attaining his pragmatic goals, namely to call a halt to what he believes is a practice that will unlikely benefit any majority of pre-lingually deaf children. Indeed, if we look at deaf history, the case of Bell may illustrate that this concern is rather legitimate.

The argument is therefore not so much about parents' moral character or essentialist definitions of identity and culture, but about a child's best-interest - we will elaborate on

this in the next section. This is true we believe for minority advocacy in general and it is certainly true for deafness (Appiah 1996). Deaf culture foundationalism is hence at least in part intended to replace the negative stigma of deafness with a more positive identity as well as intended to improve deaf people's interests in socio-economic terms. Corker for example elaborates extensively on a foundational view on identity, yet ultimately retreats to a rather pragmatic discussion on "the experience of oppression" (Corker 1996). Indeed as such Deaf culturalism should be paid tribute since it has realized quite some landmark achievements, such as a positive Deaf identity, the introduction of Sign language in many deaf schools, the availability of Sign translators and beneficial legislation such as the American Disability Act. Deviance from deaf ecology prescriptions is thus not so much an "immoral" decision, but rather believed to be an "unreasonable" one. Lane likely recognizes the powerful influence of the pitiable view on deafness. Furthermore, he likely recognizes that the inconsistent "reality" of deaf adults may only contribute to this. The fact that, contrary to mental disability, some deaf adults succeed in spoken language and succeed in attaining independence in mainstream society and the fact that cochlear implants are depicted as a way to facilitate the odds, risks that many parents give into an oral orientated approach. Perhaps Lane feels that such an approach will harm more deaf children than it will benefit. If one sets out to prevent such an event, reasoning about pragmatics is unlikely to be as convincing as counter-factualizing or the foundational moral argument of identity and culture.

It thus seems that DC-ID functions as a counter-narrative to the predominant "medical view" on disability that is of potential harm to deaf children's best-interest and that has been symbolically resurrected through the introduction of cochlear implantation (Blume 1997; Lane 1992). This is a popular stance in disability literature (Goffman 1963). Rather than categorically disclaiming the negative impact of disability, these studies aim to relativize and re-shape the dominant social narrative of disability by contextualizing the concrete disability experience. As such the Deaf culture discourse attends us on the shortcomings of pervasively viewing deafness through the perspective of disability and defectiveness and prompts us to look beyond our prejudices. The narratives of Deaf adults are a valuable attribute in this context. Deaf people are even proud to be deaf and do not long for reparation of their hearing impairment. Deaf adults teach us a different view on deafness; a view that is considerably less pitiable than many of us may conceive possible. As such the individual stories of deaf people allow us insight into the true and individual experience of being deaf. Others, such as Sacks, counter-factualize through a focus on the "miraculous" aspect or "gee-whiz" potential to amaze, inherent to some (sensorial) disability experiences. In the context of deafness this often implies a luxuriant attention to the unique language system of many deaf people, Sign language (Sacks 1989).

Many have opposed a foundational approach to minority advocacy and this opposition is highly relevant to Deaf culturalism as well. The danger is that these arguments are so convincing that they come to lead a life-of-their-own. Gutmann also

identifies this tendency

> But sometimes the advocates seem to suggest that their aim is to certify or encourage group identity for its own sake (Gutmann 1996a, 153)

As such the strategy of counter-factualizing may end up in a new truism in which being deaf is "too tightly scripted" and any route beyond the prescriptions of deaf ecology is excluded (Appiah 1996) Indeed Appiah feels that this threat to "go imperial" is rather real

> There will be proper ways of being black and gay there will be expectations to be met, demands will be made It is at this point that someone who takes autonomy seriously will want to ask whether we have not replaced one kind of tyranny with another [ ] And that would allow us to resist one persistent feature of ethnoracial identities that they risk becoming the obsessive focus, the be-all and end-all, of the lives of those who identify with them They lead people to forget that their individual identities are complex and multifarious – that they have enthusiasms that do not flow from their race or ethnicity, interests and tastes that cross ethnoracial boundaries (Appiah 1996, 99/103)

In the case of deafness this threat seems particularly real if foundationalism is connected to or intertwined with the acceptance discourse that we discussed in the previous section, if the foundational arguments become the backbone of acceptance Hence, instead of enlightening us in our consideration of deaf people's best-interest, it may evolve in an encompassing ideology instead There is a danger that a foundational Deaf culturalism comes to lead a life-of-its-own and as such loses contact with its original pragmatic strategy (West 1993) If we look at the situation in the Netherlands today one may tentatively conclude that this has indeed occurred In a time-span of about 30 years, deaf education has radically shifted from an oral to a predominantly Sign language approach with little attention to spoken language skills Indeed Stewart, a late psychologist at Gallaudet University, has claimed something similar

> This prompts me to wonder how little we have truly learned since the infamous ICED [International Conference of Educators of the Deaf] in Milan in 1880, when oralism was proclaimed by the world's professionals in deaf education as THE answer to the educational needs of deaf children Ironically, today the pendulum has swung in the opposite direction signing without voice, particularly ASL (or the version of ASL that doesn't follow English), has seemingly replaced oralism as THE one great answer in the education of all deaf children (Stewart 1998)

The low-challenging axiom that parents described also seems a rather unwanted outcome of Deaf culturalism The case of cochlear implantation is perhaps the best example of where Deaf foundationalism took a questionable turn Rejecting cochlear implantation *even* if the implant were "perfect" seems rather diametrically opposed to a best-interest approach, at least when we restrict ourselves to the best-interest of young children that lack an established identity As such it appears that what has begun as a counter-narrative

has been solidified in how the argument has come to function in deaf ecology. Rather than being a celebration of the positive subjective experience of deafness, it has been molded into an encompassing and rather coercive discourse and as such falls victim to the same critique that has been spawned in the context of quality of life research. Rather than teaching us that the subjective experience of deafness can be rather different than most hearing people expect, it has become a prescription on how one *ought* to be deaf. Deaf culture foundationalism can thus potentially harm deaf children's right to an open future. It clearly can harm parents, since it caused many of them great and intense emotional confusion and agony. Finally it may prove harmful to deaf adults as well as they may find that the hallmarks of Deaf advocacy have been paternalistically offered to them for the sake of softening their pains. There is another distinct danger to the arguments raised by Deaf culturalists that we should address. The indignation that these arguments may spur, may lead to the falsification of the object that these arguments were meant to defend. Identity and culture arguments are meant to defend Sign language and criticize cochlear implants. Yet disagreement with these arguments does not refute the value of Sign language and does not legitimate cochlear implants. If the genuine convictions of Sign language advocates are pragmatic, we ought to return to this pragmatic level if we want to say something about the legitimacy of this object. In the next section we will abandon the foundational DC-IC discourse and pragmatically focus on best-interest instead.

BEYOND THE FOUNDATIONAL RHETORIC

Introduction

In the previous section we argued that in considering a life plan for deaf children, the key issue should preferably be their best-interest rather than essentialist or foundational arguments like "identity" and "culture" or parent-based virtue demands such as "unconditional love". This is not to say that the arguments presented by Deaf culturalists are reprehensible, rather the contrary: beyond foundationalism they enrich - as we will show - our view on the best-interest of deaf children and have attained several valuable goals in their quest. We argued that opponents of cochlear implantation, even those that oppose a "perfect" implant, likely do so based on pragmatic grounds vis-à-vis a deaf child's best-interest. Lane and others apparently feel that, given the current state of affairs, cochlear implantation is unlikely the most effective or most reasonable route to safeguard a deaf child's best-interest. The fact that even the theoretical case of a "perfect" implant was rejected, we viewed as a strategic counter-discourse intended to call a halt to the natural appeal that implants may have on parents. However if we restrict our moral space to that of a deaf child's best-interest, we need to define this concept in more detail before we can proceed. Several issues in particular must be addressed.

Firstly, we need to define if we will only allow a child's interest, or that we include the parental perspective as well. In child advocacy two extremes can be identified: those that argue for a strict child-centered approach, and those that advocate the constitutional right of parents to raise their children conforming to their life-plan. Yet, the two may also intersect as we showed in the case of racial minorities: as we illustrated, only considering the interest of a child can lead to rather questionable practices, which explains why this is an issue of concern in child-advocacy literature. We will argue that both perspectives need to be included in a fair approach to child advocacy issues, such as the one under scrutiny in this thesis.

Secondly, we need to define which values we include in our appraisal of best-interest. As we will illustrate, in its rudimentary form the best-interest argument is inclined to evolve around a rather narrow range of liberal values. We will attempt to draw a more detailed and integrated perspective of the values that matter in general child advocacy by including the "communitarian" perspective, and illustrate that any final appraisal of a concrete case depends on contextual factors. Having said this, we will continue to analyze if the paradigm of general child advocacy is applicable to the case of the disabled uncomplicatedly. We will do so by referring to the case of the profoundly mentally retarded, since much of the literature on this issue refers to this specific context and because of its illustrative power. The case of the profoundly mentally retarded illustrates both the insufficiency of general liberal child advocacy as well as the distinct differences with the case of deafness.

Thirdly, we will need to define how cochlear implants and the advocated alternative of Deaf culture materialize in the theoretical context that we have drawn. Neither cochlear implants nor Deaf culture are suitable for a foundational approach, as we discussed in the previous section. Thus, once we have defined the relevant interests that are at stake and have formulated a reasonable value-set, we can proceed to analyze how real-life cochlear implants (which are not "perfect") and the Deaf culture alternative emerge. This will be our main objective in the eighth and final chapter. Finally we will depict parenting of a deaf child as a profoundly eclectic effort. As we will show, such an approach will not yield uncomplicated monolithic solutions.

General view on parenting

A key issue in defining the moral space of parenting concerns the relation between parent and child itself. If parenting is about a child's best-interest, how encompassing should we view this? Focusing too strongly on a child's best-interest seems to have some potential liabilities, as the infamous busing-project perhaps illustrates. Yet, conceiving of parenting as something that is fundamentally the responsibility of parents and they alone, also has certain hazards. This has resulted in quite some debate in parenting literature, in which two extreme positions can be identified.

On one side of the spectrum one will find those who advocate the sacrosanct position of the biological family, which renounces any intrusion. On the other side are those who depreciate the position of the biological family based on, for example, historic, anthropological or social grounds to consequently argue less in favor of parental autonomy and more to the benefit of the individual child (Skolnick 1998). Both extreme positions seem to have cultural correlates. Most people will likely agree that parents have a large degree of freedom in raising their children, as may be illustrated by the aversion that child-custody cases can trigger. The fact that others can intrude our family life and the potential paternalism that underlies such an event, apparently fills many of us with disgust.

On the other hand, talking about the best-interest of children in modern society appears to make reference to "romantic" visions on children. Children are thought of as infinitely innocent and deserving of the "best possible" care and future opportunities. Our modern child-rearing practice is characterized as being highly "child-centered": if the suggestion is made that certain children are not getting the "best deal", this will likely trigger many to join battle against it (Verkerk 1993). There have been many who have underscored the "constructivist" nature of the biological family, a position that often stresses how the biological family can fail and undermine the "best-interest" of a child. Examples of overt neglect often supply the ammunition for such a view. Indeed, the fact that there is a genetic bond between people does not automatically imply anything really. Skolnick refers to the biological nuclear family as a "cultural icon" (Skolnick 1998).

Historians may illustrate that not so long ago, the nuclear family as we know it today did not exists Anthropologist may illustrate that our concept of family and the relations inherent to it are not universal Sociologists may illustrate how the construction of the family is very closely related to social realities What many of these initiatives have in common is that they view the family as a functional unit with a formal task – namely to protect and optimize children's best-interest - rather than an emotional or existential unit in which parent and child are closely interwoven (Skolnick 1998) This view has the concrete advantage that it grants the child a moral space of its own, and can as such represent the case of neglected children Yet a potential liability is that it can lead to "formal" and highly child-centered solutions, which are blind to the threat of paternalism that we discussed previously, blind to their own liabilities and fallacies and unproven premises, and are blind to the interwoven nature of parent and child within the affective family unit As we argued before, the busing-project and segregation of Amerindian and Australian Aborigine children are illustrative of this potential fallacy We would suggest that the claim that hearing parents should "give-up" their deaf child to a residential school or adoptive Deaf family, anecdotally encountered on Internet discussion groups, is also blameworthy of a similar shortsightedness (Stewart 1992)

In an attempt to counter the view on the biological family as a merely "functional unit", Archard lists several arguments in support of the biological family The "proprietary argument" argues from the position of the parent - it is a "constitutional" parental right so to say - and departs from the situation of the pater familias, of the father who "owns" his children Yet this argument is not particularly convincing in our modern climate and has cast a "long shadow over much thinking about parental rights" (Archard 1993) Of stronger support are the "interest argument" and the "least detrimental argument" The latter two arguments support the vision that the nature of the relation between child and natural parent is as such that it in itself safeguards a child's best-interest

> Many commentators believe that the child's best interests are in fact served by growing up with biological parents, and that "natural bonds of affection" lead parents to care for their children in a way that no "stranger" could (Skolnick 1998, 239)

These arguments depart from the assumption that blood-ties by their very nature imply a level of devotion and involvement so great that it is unlikely to be surpassed by any alternative environment

> I have given reason for thinking that the separation of a child from its parents may have serious costs It is even more certain that a radically disrupted childhood, one without a relatively stable and permanent context of affectionate care, can be harmful There is no reason, in short, to think that a child's best possible upbringing requires seeking out at each instant its best possible rearers and moving it to them (Archard, 1993, 107)

Buchanan and Brock also support this view

> Members of a family typically have a special responsibility that emerges from the intimate nature of their union and long-standing patterns of cooperation (Buchanan 1989, 140)

In the current socio-cultural climate we think it can be fairly stated that most parents indeed value their children deeply children have become of existential value to their parents as Hays suggests (Hays 1996) As such, Archard and Buchanan's arguments strike as sound indeed In general, given the lack of solid and consistent evidence (beyond the most serious of negligent situations) favoring one child rearing style as opposed to another, we do not see by which right infringements into the biological family can be justifiable (Mnookin 1979, Buchanan 1989)

> Over the years this study has generated several significant research findings, but the most surprising of all was the difficulty of predicting what thirty-year-old adults would be like even after the most sophisticated data had been gathered on them as children the researchers experienced shock after shock as they saw the people they had last seen at age eighteen It turned out that the predictions they had made about the subjects were wrong in about two thirds of the cases! How could a group of competent psychologists have been so mistaken? Foremost, the researchers had tended to overestimate the damaging effects of early troubles of various kinds (Skolnick 1973)

Without such evidence, the risk of imposing one group's political views on others seems very large indeed Indeed, under the banner of a child's best-interest, prejudice has historically characterized many infringements of the parent-child relationship (Skolnick 1998, Raphael 1998, Ruth 1989, Turner 1972, Blustein 1979) Abolishing this premise would imply a neglect of the reciprocal intimacy between parent and child and the resultant beneficial situation for children while opening doors for gross interference by state agencies

Gardening and guardian values in child advocacy

If we abandon foundational arguments dictating how we "ought" to deal with deaf children and focus on what benefits an individual child the most, we must define which values we are to gauge in such a pragmatic process Now, some advocates of cochlear implantation may argue that, surely, "hearing" is an unyielding candidate We will focus on the value of hearing in our final chapter and will in this section restrain ourselves to the general framework within which the issue is discussed in child advocacy To jump to the value of "hearing" before we have actually explored the *general* outlines of the child advocacy case, is rather premature we need to agree on the general values at stake before we can discuss the specific merits and liabilities in the context of cochlear implantation

Our empirical material illustrated that parents appealed to a range of values in their parenting career parents spoke of gardener values - such as affective and social-relational concerns - and were sensitive to evaluative notions such as contained in the

"Good parent" argument directly around the diagnosis and when language and school decisions had to be made Values alluding to guardianship - such as self-reliance and autonomy - came to the forefront when questions were asked in the present Sometimes envisioning the time when they would no longer be able to care for their children, parents became increasingly focused on their child's ability to stand on his or her own Hence, parents of older deaf children often shifted from gardening to guardian values This shift in perspective is not a surprise if we consider the general literature on parenthood Van den Boer notes that modern parents experience a growing responsibility towards their offspring and that society in turn has amplified this situation by granting parents responsibility for the choices they make (Van den Boer 1997) This responsibility does not limit itself to the emotional or relational context of gardeningship but includes concrete future goals as well O'Neill argues that the conditions of care are paramount mostly during the early years of life (O'Neill 1979) As a child grows older, the "liberal" perspective or guardianship becomes more dominant autonomy and attainment of a stable and self-chosen identity are considered two cardinal pedagogical aims of adolescence (van der Slik 1996, Rispens 1996) In a Dutch population, Rispens found that in the earliest years of child-rearing parents tend to be mostly "supportive" in their stance Yet as a child grows older, parents become less supporting and more demanding (Rispens 1996) Dutch parents value their emotional bond with their child most highly, though this value decreases as their child grows older (Rispens 1996)

The ultimate measure of guardianship is often verbalized as "independence" and "autonomy" parents raise their children with the ideal of making productive and independent citizens of them in the future (Ruddick 1979, van den Boer 1997, Larson 1998) In a study with 788 Dutch respondents, van der Slik reports that this is indeed the most prevalent parental goal amongst modern parents (van der Slik 1996) Yet if "autonomy" is a cardinal value that parents ought to look after, one may ask "autonomous to do what"? If we want to proceed beyond the level of very global parenting theory and want to make our case more concrete and applicable to real-life cases, we must provide an answer to this question it seems – even though we would not advocate that answers become too specific and encompassing, since this would restrain us from incorporating the peculiarities of a specific case In general liberal terms, one could argue that the answer to this question is to be able to choose one's life-script autonomously, which requires respect of "liberty" through safeguarding "physical and mental integrity" Yet it also requires the facilitation of certain basic or reasonable "opportunities" – the two being strongly interrelated (Gutmann 1996a, Buchanan 1989)

> So in any particular society children need to develop certain general abilities and traits in order to be able, as adults, to enjoy a reasonable range of opportunities from among which to choose their own particular aims, pursuits, and life paths (Buchanan 1989, 228)

Some sub-goals related to opportunities are listed below

Guardian goals (Van den Boer 1997, 240)

- Physical survival of the child
- Development of a potential to be economically independent as an adult
- Development of other capacities so that the child may acquire certain values, such as prestige, a certain prosperity and self-realization

A lack of access to basic opportunities implies that the liberty to determine one's life-script becomes curtailed, which is most evident in the case of "health" and "physical survival". Parents must thus raise their children in such a way that access to these basic opportunities is provided in, while it is society's duty to guarantee that parents are actually able to do so by for example providing equal access to health-care and schools. In this context Ruddick speaks of parenthood as the "provision of life prospects", which includes both the liberty of choosing one's identification-path as well as providing access to basic opportunities. Yet this notion is just as unclear as the autonomy demand. If parents are to provide their children with "life prospects", how are we to conceive of life prospects, how many do parents need to aspire for and how "self-serving may a parent be in fostering a child's life prospects?" (Ruddick 1979)?

The addition of the prefix "basic" or "reasonable" is rather crucial. It can safeguard against excessive assaults on a child's liberty to self-determine their life-script, in the name of "optimizing" his or her opportunities. For many authors, "optimizing" opportunities is not a moral demand we can make on parents, even though it may be a popular cultural value and also surfaces in some more extreme egalitarian writings vis-à-vis children from families with limited resources (Ericson 1992). As such this provides protection of parents against overt intrusion and paternalism, in the case of families with relatively limited resources or those with specific principles or faith. Making sure that children have access to basic schooling is something we can demand from parents, yet demanding that all children attend university and have access to high-profile careers is unreasonable from this perspective (Buchanan 1989; Gutmann 1987). Nonetheless the controversy over what we ought to consider "reasonable" liberty and "basic" opportunities seems to continue. Ruddick discerns two extreme positions in child advocacy, which more or less represents a reappearance of the two extreme positions on parenting that we discussed in the previous paragraph. The (extreme) traditionalist view states that parents need only provide one life prospective, typically that of the parent. The drawback of this approach is that it potentially merges parent and child interests in favor of the former and as such potentially opens the door for "eccentrics" by parents, which may not benefit the child's liberty to choose his or her own life-path and may also curtail his or her access to basic opportunities. It does however guard parents' constitutional right and protects against paternalism, and is perhaps fairer to the interrelatedness of parent and child in discussing best-interest. The (extreme) libertarian view on the other hand accentuates a child's right to an individual future "choice" and therefore feels that parents need to aim for as many life prospects as possible. But does this imply that parents cannot raise their children in concordance with their own philosophy or religious convictions, because this will limit their child's liberty to a self-determined identity? And

does this imply that parents with limited resources are at risk, because they may be likely to limit their child's access to future opportunities? It seems that an extreme libertarian perspective is at risk of "upgrading" the opportunities that parents should provide in from "basic" to "optimal" Though it does not provide sufficient conceptual translucency to dodge this problem altogether, we do feel that the previously discussed importance of the prefix "basic" or "reasonable" as well as an awareness of parents constitutional right and the interwoven nature of parent and child within the family-unit can protect us from such unreasonable assaults Hence, even though these two extremes are interesting from a theoretical point of view, their applicability is rather questionable we should include both perspectives when dealing with concrete dilemmas

Ruddick also feels that both conceptualizations have merits and seeks to integrate them into a view which "honor[s] parents' productive desires and children's needs for lives of their own which neither require nor reject parental approval or support" (Ruddick 1979)

> Hence to lead a life of one's own, a person requires various capacities of emotion, imagination, and will A life of one's own does not, however, require rejection of parental ways or separate domicile or occupation It is enough that whatever the similarity and the parental influence, a child's life comes to have its own endorsement, not merely that of its parents (Ruddick 1979, 129)

Hence, Ruddick's answer is that parents need to aspire life-prospects that yield an "individuality" that is "acceptable" to both parent as well as child, as co-determined by the prospected futures of both parent and child The addition of the second requirement underscores that "acceptability" – or the determination of what constitutes a "reasonable" life prospective in which parents should provide - is not restricted to the immediate parent-child context Thus, in determining if both parties could "accept" specific life prospects, one needs to consider not only the current context but the prospected context as well Ruddick feels that modern western societies provide little reason to assume "stability" over time and feels that this situation has led many modern parents to option stronger for a libertarian view on parenthood Though this does not imply that parents need to prepare their child for every possible future circumstance, Ruddick underscores that they do need to engage *actively* in searching for "possible choices" their child could reasonably make as well as asking themselves if they - in time - could reasonably approve of these choices If the answer to both questions is positive regarding a specific life prospect, Ruddick feels that "some provision" for that prospect should be included (Ruddick 1979) Ruddick believes that the added burden on parents induced by this view is not so great since "parenthood is prospective work from the outset" (Ruddick 1979)

The case of the Amish

The case of the Amish is perhaps interesting in this context, since it likely challenges those inclined towards an exclusive libertarian perspective on parenting. In the legendary 1972 Wisconsin versus Yoder case, the state of Wisconsin brought three Amish fathers to trial because they limited their children's education to 8th grade of high school based on their religious conviction (Reidy 1998). The Wisconsin Supreme court eventually supported the Amish and allowed them to continue their practice. Based on an exclusive liberal perspective, the supreme courts ruling may spawn surprise. After all, is it not rather obvious that the Amish harm their children's best-interest with their refusal to allow them to attend mainstream high school education? For clarity purposes we must state that what was at stake in the Wisconsin versus Yoder case, was the educational issue alone and not the Amish lifestyle - though some may argue that this is a questionable assumption. Yet even if we expand our perspective to the Amish lifestyle, univocal critique is hard to formulate if we look further and beyond strict child-centered liberal reasoning – if we open our perspective beyond prejudice and focus on the details of the case rather than on an ideological paradigm.

As we argued, parents have a duty to provide their children with "reasonable" liberty to choose their life-paths and should provide them with at least "basic" opportunities. Reasonable liberty, as we said, refers to both a child's "prospected future" or possible "choices" as well as parents' ability to reasonably accept this. The latter implies that parents need to be creative and stretch themselves. But there are limits to this demand. Firstly, not *all* life-scripts provided by parents are necessarily limiting and harmful to a child's right to self-identify. This likely applies to most of the "common" values that parents want to raise their children with. It seems unlikely that raising a child with the bible, with leftist values or in a gay relationship comprises a serious limitation for a child to self-identity in liberty as an adult, and as such seems rather benign. From this perspective it should be noticed that the Amish *do* allow individuals to actually leave the Amish community (Reidy 1998). Yet even if limitations are at stake, such as may be argued in the case of the Amish, lenience may be an appropriate attitude nonetheless. If the provision of a specific identity-script or "prospected future" seriously and honorably damages parents' narrative continuity and this damage is of significant proportion, we have two "rights" opposed or conflicting and cannot simply demand that parents provide that specific script nonetheless (Reidy 1998). This is likely mostly relevant to certain secluded religious groups, such as the Amish. In spite of these liabilities, the Amish case leaves the conflict between parents and their children unresolved, which can lead one to ask "which interest should prevail"? Authors such as Reidy feel that ultimately, those of the Amish children should (Reidy 1998). Yet, there is another complicating factor that we should consider: demanding that Amish parents comply with *our* standards may cause, similarly to what we said in the context of racial minorities, a serious breach between parent and community on the one hand and the child on the other hand, which is unlikely to benefit such a child as it potentially harms their "right" to a "stable socio-

cultural identification" (Reidy 1989; Kymlicka 1989). An additional problem is that "reasonable" liberty also refers to a child's "prospected" future choices. In the case of the Amish, it can be argued that is has been historically shown that most Amish children actually choose to self-identify with the Amish way-of-being, hence making this a "likely" choice indeed, which in turn suggests that we are not curtailing a child's liberty to self-identify really but are rather catering to it.

A next issue is the issue of "access to opportunities", which became a central issue in the Wisconsin versus Yoder case (Reidy 1998). Indeed, the Amish life may limit future opportunities. Enforcing community life and restricting schooling to 8th grade is unlikely to yield many physicians or lawyers for example. Yet, as we argued previously, this is not a requirement per se. If we restrict ourselves to "basic" or "reasonable" opportunities, the Amish do rather well, and it is this point precisely that they successfully defended in the above mentioned case.

> It may seem strange that failing to send children to school past the eighth grade would be a permitted or acceptable practice. But the Amish society is itself a school. They train their young people vocationally -- how to be homemakers and farmers, carpenters, and tradesmen from very early ages. By the time an Amish girl is twelve years old she knows how to cook a meal for a whole crew of Amish workers, and a young man knows farm operations by the time he is a teenager. The Amish therefore have practically no unemployment, since their society is a vocational school. The Amish operate one-room parochial schools and are taught by teachers with only an eight-grade education. However, the teachers have learned how to be teachers with on the job training by an older and experienced Amish teacher. The Amish pupils have been tested with standardized tests by the U.S. Office of Education, and the pupils usually perform above the norms when compared to public schools pupils in their communities. The students are not therefore educationally deprived. (www.holycrosslivonia.org)

Indeed, the court appeared to accept this train-of-thought and reasoned that, even if a child would leave the Amish community, they were unlikely to "become a social burden", which exempts them from the critique that we verbalized previously: we cannot endlessly allow appeals of "partial citizens" to the "right" of access to opportunities if people deliberatively create "differences" or "identities" that make them into a social burden, as the case of "acting white" illustrates (Reidy 1998; Gutmann 1995).

The "prospected future" in the context of deafness

Hence in preparing children for "autonomy", parents ought to consider the possible future life-scripts that their child could come to choose while also guarding his or her basic opportunities. Yet in the case of deaf children, this issue becomes compounded because of the handicap involved, which likely explains why the debate is particularly intense in disability literature. What is the "prospected future" of a handicapped child and

how are we to perceive the "possible choices" that such a child will face, and which we have to provide in? While parents of "normal" children may rear their children almost intuitively, based on the assumption that there is considerable continuance between parents' current life and the child's prospected life or navigate on their imaginative powers to envision potential alternatives, this is not necessarily the case for parents of a disabled child

Indeed, as we have shown in the previous section, Lane suggests that this is a fundamental problem in the case of disability, as he reasons that parents that option for future-scripts anchored in mainstream society are misjudging their handicapped child's most likely identification path – thereby harming his or her liberty to choose his or her own future Moreover, Lane feels that aiming for mainstream life-scripts will harm a child's basic opportunities, since deaf children will simply fail in the mainstream Authors such as Lane hence seem to hold that parents cannot navigate on their own lives and values in establishing their child's "prospected future" Additionally, it seems to be assumed that parents' imaginary powers will also fail them in defining such futures

> However, it is open to question whether a DEAF child's values as an adult will closely resemble those of its hearing parents (Lane 1997)

As such Lane seems to render the biological family "incompetent" to represent their deaf child's best-interest, thereby opening the door for intervention – though this judgment may be too harsh (Buchanan 1989) While Lane does not actually advocate intervention, he does suggest that this problem can be overcome by letting adult Deaf individuals co-decide for deaf children that we at least include their views in our deliberations (Lane 1997) Yet it seems that some Deaf adults themselves *have* actually aimed at intervention through "substitute-judgment" (van Veen 1993, Musschenga 1987)

Under the conventional ethical meaning of the concept of "substitute-judgment", the will of an incompetent person, such as a comatose patient, is reconstructed based on prior autonomous functioning or a previous life-plan Yet, in the case of deaf children, no such concrete history exists, which makes the threat of a paternalistic and biased reconstruction rather real (Musschenga 1987) As such authors like Buchanan feel that the concept of "substitute judgment" is not applicable to young children who never had such a history (Buchanan 1989) Under conventional circumstances, such a situation leads to the operationalization of the juridical concept of "best-interest" instead (Buchanan 1989) In this concept a "reasonable person" sets the benchmark, though the results are likely to be verbalized in rather global terms to avoid the problem of paternalism (Mnookin 1979, Musschenga 1987, Buchanan 1989)

Perhaps some Deaf adults feel that they may function as that "reasonable person" instead of, or as a substitute to, parents Deaf adults, so it has been claimed, historically value their deafness and hence we should make an effort to reason from this perspective

rather than the pitiful stereotype dominant in society, which is likely intrinsic to parents as well. There certainly is some merit to such a position, since the case of Deaf adults can give us a closer-to-life look at what may benefit a young deaf child best. Yet there are potential pitfalls to it as well. As we argued in chapter five, we do not find this "state" of the adult deaf particularly convincing, while convincingness is a crucial issue here. Buchanan feels that when considering the biological family's judgment as potentially inappropriate it is essential to be informed about:

> The strength of the evidence that most reasonable and informed persons would choose differently from the family in applying the best interest principle. (Buchanan 1989, 145)

Convincingness is lacking we feel, which makes a parallel to the case of the Amish not entirely sound. Even though many deaf people do identity with Deaf culture, this is an exit-option really. With a "perfect" implant it would seem highly unlikely that a deaf child would self-identify with Deaf culture. Now one may argue that this is rhetoric, since with a perfect implant a deaf child will never actually taste Deaf culture, thus excluding it as a realistic "choice" or "prospected future". Yet we do have a "natural experiment" that disproves this: hearing children of Deaf parents identify at least bi-culturally rather than mono-culturally, even though they have been culturalized in Deaf culture (Bull 1998). This illustrates, we feel, that if a realistic choice would be presented to deaf children, which a "perfect" implant would, many of them would actually choose for a "prospected future" in hearing society. The "choice" for Deaf culture is one that deaf people have made very much related to their limited abilities to realistically choose another identification-path. Broekaerts found, for example, that the higher a deaf individual was schooled, the smaller the chance that he or she would function primarily as culturally Deaf as an adult. This also seems to support the thesis that Deaf culture should not be perceived as a goal in itself but rather as a valuable yet secondary structure (Broekaerts 1994).

Furthermore one should consider that the observed "difference" of Deaf adults is at least to some degree socio-historically constructed, which is meant to denote that it is the result of a system that has wrongly patronized, isolated and under-schooled the deaf early on - regardless of language of instruction (Appiah 1996). Given the institutional foundation of the biography of many of today's Deaf adults, as well as the fact that the societal situation of that population is far from ideal, "recognition" of that biography or history cannot a priori be taken as implicating that it should be literally repeated in future generations – which allowing Deaf adult's as "reasonable persons" could potentially result in (Taylor 1994a). The fact that Deaf adults express that they do not have a "need" for identification beyond Deaf culture and even prefer their Deafness over hearing society is a direct result of their history, and cannot be taken as implying that we should not provide the *potential* for identification beyond Deaf culture, if this can be reasonably attained. In part, this assessment is congruent with Cribb's critique on navigating unilaterally on self-reported well-being in quality-of-life research (Cribb 1984). Cribb

feels that by doing so, and by omitting more objective standards into the equation, one ignores the fact that people can have "needs that are beyond their momentary perspective and their momentary experience of needs" (Musschenga 1987) The fact that people with a disability succeed to adapt and self-report positive quality-of-life, should not too hastily be interpreted as saying that we need not offer opportunity for change Bertling, a critical deaf author, has also voiced this notion rather convincingly

> If I had started my early schooling at the deaf school, I seriously doubt that I would have the same success I enjoy today By not having the basis for comparison, I would probably be more favorable toward the deaf culture It would be difficult then to criticize the only way of life I would have known, even if faulty The outside hearing world would have seemed so distant and unattainable with my having never lived in it This book would never have been written [ ] Deaf children deserve a much better fate than the one "history" has provided (Bertling 1994, 53/97)

Furthermore, as we have argued, the very topic of rearing deaf children has become the stake of Deaf liberation movement and is as such highly politically loaded Archard's critique on "self-justifying paternalism" – "paternalism which changes others so that they approve" - may as such apply (Archard 1993, Taylor 1994a) While the "label" of Deaf culturalism may proof vital to identity politics, it can also perpetuate itself since the label will "shape the intentional acts of (some of) those who fall under it" (Appiah 1996) Hence, the "state" of the adult deaf population does not convincingly confirm Deaf culture as the "prospected future" of deaf children This is congruent with the position that many respondents upheld The content of "identity" that parents envisioned appeared closer to liberal conceptions of identity it was desired to be non-restrictive, not a "mental prison" but rather constituting only one aspect of their child's identity, a valuable aspect perhaps Parents appear to be somewhat supported in their stance by the young deaf generation, who are supposedly more individualistic and express less interest in Deaf culture in 1998, a youth festival was organized in the Netherlands which centered specifically on the decline of interest of young deaf individuals, measurable by a decrease in membership to local Deaf clubs (Jongerennieuws 1998)

Yet in spite of this critique, these arguments are not a sufficient answer to our problem of defining "prospective future" in the case of the disabled in general and deaf children specifically We may disagree with the *justification* of Deaf culturalism through the paragon of Deaf adults, yet this does not rebuff that Deaf culture may very well represent the only reasonable "prospective future" of deaf children nonetheless Even though much has changed in deaf education, the possibility is still very real that deaf children will "choose" to submerge in Deaf culture in spite of our objections, even though one can question if this truly represents an expression of "liberty" or rather a pragmatic inevitability or "exit option" Even though children with a "perfect" implant would "reasonably" choose for mainstream society, cochlear implants are *not* perfect, which leaves the possibility of Deaf culture identification wide open This implies that we need to look at the suitability of liberal values vis-a-vis the case of people with a

disability, beyond our disagreement with the advancement of Deaf adults as the uncontestable "reasonable persons" to represent deaf children. This entails an honest and pragmatic evaluation of the "reasonability" of "prospected futures" of deaf children – which requires openness to the empirical facts of deafness, cochlear implants and Deaf culture, something we will elaborate on in the final chapter. Clearly, we do not a priori believe that Deaf culture is inexorable on empirical grounds – if we did our discussion in chapter eight would be rather futile. Yet in some cases the inappropriateness of our liberal perspective on childrearing is rather obvious, as may be argued to be the case in the context of severe mental retardation. To uphold values such as the "liberty" to choose one's own life-path and facilitating "opportunities" in the case of children who are deeply retarded, strikes as peculiar indeed. Sending a deeply retarded child to mainstream schools to "improve" his or her liberty to self-identify, for example, may seem like mockery even. It seems rather evident that such a child will never identify with any "common" identity, and as such this may raise the question what "benefit" mainstreaming serves really. We will scrutinize this issue in the next section. This will allow us to illuminate the genuine moral problems that arise in the context of people that do not seem to "fit" in the common view on childrearing that we discussed so far. It will also allow us to shed light on some of the answers that have been formulated to deal with these problems. Furthermore, it will allow us to continue to analyze where the idea of the "inappropriateness" of our common liberal values can – thus not "must" - lead us to if they become "foundationalist". Finally, we will apply this insight to the case of deaf children to argue that even if our liberal values were "inappropriate", we should be careful not to thrust them aside categorically.

Gardening and guardian values in the case of disability

Though we argued that Deaf culturalists often legitimize their advancement of a specific "prospected future" based on the example set by the adult Deaf population, some have meticulously scrutinized the best-interest issue beyond this claim, be it mostly vis-à-vis mental retardation (Reinders 2000). Literature published in the field of mental retardation cannot simply retreat to a "prospected future" as Deaf culture advocates have, and must therefore explicitly analyze the issue of best-interest from a broader perspective – which we feel is valuable in the context of deafness as well. A central question thus is: does our liberal view on a child's best-interest, with its focus on the liberty towards self-determination and the right to opportunities work uncomplicatedly in the case of mental retardation? If not, what alternatives can we think of? Do we need a different pragmatic working-model that fits into our liberal spirit, or must we revise the liberal view on best-interest altogether?

The situation of profound mental retardation is distinctive, since the centrality of the concept of "choice" becomes deeply problematic in this context. Extreme liberalism, as we argued, seems to equate best-interest to the facilitation of individual "choice" in

terms of identity and opportunities, yet this assumption becomes sticky and rather scanty in the context of mental retardation. If we focus on "choice" to rigidly, hence much in the same way as we would in the case of non-disabled people, we risk ignoring the merits of the resultant of the choices made in terms of an individual's best-interest. A similar situation can be encountered in adult psychiatry. Catering to the liberal value of autonomous choice is not only questionable in terms of the concept of autonomy itself (how autonomous is a schizophrenic patient?), but more importantly can lead to situations in which the inadequacy of the assumed correlation (by liberals) between "best-interest" and "choice" is painfully exposed. If a schizophrenic or deeply retarded patient "chooses" to isolate and neglect him or herself, how much does this *really* serve his or her best-interest? Would such a person not have been better off if we curtailed his liberal right to choose, to so facilitate a "prospected future" that serves his best-interest more optimally - though risking paternalism? The problem of paternalism is essential however, though these thorny questions also illustrate that bowing our heads to the threat of paternalism is not a reasonable position either.

If we consider curtailing liberal rights, it seems appropriate that we do so based on more than our intuition alone. Indeed Lane is correct in the basic assumption that our intuitions can fail us if we are considering an out-of-the-ordinary case, such as the one of retarded citizens or psychiatric patients. Our intuitive claim that enrolling a retarded child in mainstream education is "mockery" may well also be symptomatic of faulty intuition. It may well say more about our own prejudiced view on retarded children, than it does about the *actual* merits of a mainstreamed retarded child (Buchanan 1989). We thus need a more convincing and colorful argument to legitimate why curtailing basic liberal rights is considered "appropriate" in a specific case. If we feel that upholding these rights "harm" a specific person, we must provide an argument *why* this is so.

One may consider this issue from a broader pragmatic perspective, for example by adding the concept of quality-of-life to the values that we discussed (Buchanan 1989). We can, for example, measure the quality-of-life of retarded children in a mainstream setting and compare this to those in a secluded environment. Yet, as we have shown in the case of deafness, such projects can still suffer from "design faults" - are at risk of incorporating a fixed and rather prejudiced (pitiable) view on a specific people. In the case of deafness we have shown that the quality-of-life approach, with its strong and one-sided emphasis on "self-esteem", departs from the assumption that deaf people are somehow entitled to more "emotional" well-being than we would demand from non-disabled children, a view that ultimately originates in a rather pitiable perspective on deafness. Thus, a quality-of-life approach is no panacea in this context. Still, we feel that we need to strain our minds in thinking about best-interest from a broader perspective than provided by the basic liberal model. Yet the interesting thing is that, both in the case of deafness, retardation and chronic psychiatry, we are not really doing this. While many authors do strain their minds over the complex moral problems that surface in these areas, many seem to do so in a foundational context: many seek theoretical

underpinnings of a specific practice, rather than self-critically examining the merits of the several available options in a specific case – regardless of our personal intuitions Perhaps there is no other way, since at the end we cannot reach any further than what our intuitions allow at least in the case of chronic psychiatry and profound mental retardation we have no uncontestable empirical "check" for our intuitions, since we cannot ask the subjects of our thought if they agree with them Yet, as we have suggested in the context of the DC-ID argument, a foundationalist approach is inclined to silence rather than stimulate moral reasoning, and is at risk of becoming a purpose in itself, which may result in a situation where we actually injure rather than cater to an individual's best-interest

As we said, ultimately no one can claim to *truly* know what is best for a profoundly retarded child We sense that there is something "wrong" in boldly applying liberal values to their case and we may seek empirical evidence to replenish our argument, yet in most cases we cannot reach much further than deliberation and tentative evidence The foundational moral problem is much more transparent however, and perhaps this also explains the previously mentioned preference for a foundational approach If a mix of gardening and guardianship represents dominant child-rearing ideology, we clearly run into problems with mentally retarded children, as they will often not be able to realize liberal values such as autonomy and self-reliance in the conventional sense (Reinders 2000) If liberal values are upheld rigidly, conceptual moral questions regarding the value of life of profoundly retarded citizens may even arise (Singer 1985, Tooley 1983, Reinders 2000) Indeed, Engelhardt speaks of "human non-persons" in this context (Engelhardt 1996) Fletcher questions if an IQ below 40 on the scale of Stanford-Binet can be regarded as satisfying the criteria of Humanhood (Fletcher 1972, Musschenga 1987) This "fact" will certainly cause parents severe anxiety, which can be well understood if we consider Musschenga's analysis of the quality of life debate

> To most authors, judgments about quality of life are not just value judgments but moral judgments For them, the boundary between human and non- or sub-human life has direct moral relevance A minimal quality of life has consequences on the moral status of life Life that is not human, or will never become human, does not need to be maintained at all cost (Musschenga 1987, 53 – translation ccw)

The same may be true for care providers in institutes They too will likely face deep confusion or moral "incoherence" if the reigning child rearing ideology is upheld, since this ideology a priori renders profoundly retarded children as "failures", even to the point of questioning their humanity (Rorty 1996) Surely to work with children that are a priori labeled as "failures" is not an uplifting thing to do, and the status as "non-humans" will likely not match with the relation that care-providers develop with these children Perhaps Musschega's statement illustrates that we do indeed need a new foundationalism in the case of profoundly retarded citizens to fence-off this kind of conclusion, which seems to be the result of a rather questionable form of "moral Puritanism" so to say A one-sided gardening or "care" discourse seems to be a prominent option, a way out of

this moral incoherence By designing a counter-discourse, which renders the dominant liberal ideology default or out of place while replacing it with a care-oriented discourse, anxiety may be avoided

Yet such a counter-discourse demands foundational underpinning unless it wants to fall victim to a rather unsatisfactory "apathetical", encompassing and essentialist "cannot be done, that's just the way it is" axiom – which is the likely hallmark of a rather far-reaching segregation of the disabled from society Indeed, Reinders states that it is commonly assumed that "these children [mentally retarded – ccw] are incapable of living an independent life, they will never be self-supporting, pursue a career of their own, build a family, and so on" (Reinders 2000) This latter option represents a "negative choice" so to say we exclude realization of guardian values from our pedagogical task not so much because we believe it should be that way or that it suits retarded children's interests best, but because we a priori feel that it cannot be done, which feeds on the above-mentioned portrayal of retarded children as "failures" rather than combating it the sense of "difference" and "failure" is exploited while the foundational problem is left untouched (Fromm 1994) Disability organizations, have lashed out at the negative "cannot do" stereotyping and the defectiveness it represents of handicapped people, not only from a symbolic perspective but also since it can clearly work against them if such a view becomes encompassing, becomes a "fixed position" that does not allow the disabled to be or act any different than prescribed (US Public Law 101-336)

> Individuals with disabilities continually encounter various forms of discrimination, including overprotective rules and policies (US Public Law 101-336)

While the merits of a care-perspective are certainly not contested, certainly not in the case of profoundly retarded children, an *encompassing* care-perspective may lead to a rather biased and patronizing form of essentializing, which in turn may legitimate overt isolation and segregation (Ten Have 1998, Wever 1997) Since it functions as an encompassing "cannot do" axiom rather than being founded on a critical analysis of the concept of best-interest, it will likely be rather perpetual The further this discourse progresses chronologically, the deeper will it become intertwined with what we normally consider the private domain Friendships, love, identity, intimate relationships all stand the risk of being included into this view, which is characteristic of an encompassing ideology Indeed, autobiographies by disabled people consistently reveal this theme (Wever 1997) Indeed it appeared that such a care-ideology dominates at least in the environment of some signing schools for the deaf In deaf literature this care-orientation can also be observed Markshark's celebrated book on raising deaf children for example, hardly speaks about the years beyond adolescence and this is rather symptomatic for deaf research (Markshark 1997) An abundance of information is available vis-a-vis the earliest childhood years and consequently gardening values yet very little has been written about adolescence and adulthood If adulthood is examined it is often in the context of socio-emotional functioning and rarely in terms of individual or societal

attainment Another well-known text written by Ogden is titled "The silent garden" which illuminates the predominant gardeningship values represented in this book Only 12 of the 313 pages deal with "independence" and even these pages hardly deal with opportunity interests but rather with socio-emotional issues such as the value of Deaf friends and Deaf culture (Ogden 1996)

Some authors have attempted to escape the "negative choice" that we depicted above by advocating a "positive" care perspective (Schwartz 1997) The lack of aims towards liberal values is encapsulated in this "pluriform" ideology handicapped citizens are "different" people for whom "different" (i e non-liberal) values apply Though it calls upon our virtue as "tolerant" people as a way of legitimating their existence, this is a rather fragile "foundation" for the same reason that we argued that "racialism" was this perspective also perpetuates the idea that disabled people are fundamentally "different" and is also at risk of becoming a coercive script Moreover, the main premise in itself can be questionable It seems to be assumed that care and empathy are essential and indispensable for the disabled, much more so than for non-disabled citizens Yet while it is rather obvious - yet preferably not too self-evident given what we said about the threat of an encompassing ideology - that retarded citizens must rely more intensively on solidarity and our preparedness to care for them than the average non-disabled citizens, these authors seem to argue beyond this pragmatic level (Ten Have 1998, Tronto 1993) Perhaps this is because it is suggestive of the "negative choice" that we depicted above David Schwartz for example, states that "culture is that with which we face pain, sickness and death" (Schwartz 1997)

> For the handicapped person who had felt abandoned, there is only one reality that will bring him back to life an authentic, tender and faithful relationship He must discover that he is loved and important to someone Only then will his confusion turn into peace [ ] It is to rejoice in his presence, it is to give him confidence in the value of his being (Schwartz 1997, 124)

Schwartz seems to reason along the "pitiable road" that we described in chapter three however He seems to suggest that since disability deprives an individual from the liberal values from which we typically measure our value as human being, we should *at least* comfort the handicapped and reassure them that we welcome and love them in spite of their disability Alden has criticized this in the context of deafness

> It is easy to define Visual Children as disabled without using any of the aforementioned words This can be done by saying that Visual Children need special schools, special education, special services, special classes, special programs, special educators, and adaptive education Visual Children don't need anything special All Visual Children need are education, educators, schools, classes, programs, and services (Alden 2001)

From our discussion so far it seems necessary to distinguish between children with a profound mental disability and other handicapped people Though the need for loving care is rather self-evident in the case of the severely retarded and as such possibly leaves us with no other foundational route than a call upon our tolerance and solidarity, this is much lesser true in the case of children with a mild mental handicap or deafness While a foundational care-ideology is likely to benefit profoundly retarded children the best, this is not necessarily true in the case of deaf children Nonetheless it seems that the same foundational argumentation surfaces in the context of deafness as well as milder forms of mental retardation Moreover, a foundational care-ideology seems a preposterous answer to the conceptual moral problems that we described in the context of profound retardation Deaf children and children with a mild to moderate mental disability certainly do have access to opportunities, though their level of access may be below "average", hence making the conceptual problem that occurred in the context of profound disability rather inappropriate We would not discard the concerns over the suitability of liberal values in the case of disabled children's best-interest, but feel that these concerns should be made explicit rather than axiomatic so to find appropriate solutions Therefore, we would advocate that we candidly scrutinize and explain why and under which conditions the dominant liberal ideology is considered unfit and why and under which conditions an alternative approach suits disabled citizens' interests best The fact that we are confused by the moral implications of upholding liberal values vis-a-vis disabled children is an inadequate motive to refrain from examining the possibilities these children have, and retreat in an ill-founded encompassing care-ideology instead Our "moral incoherence" is at best partially related to what is at stake here an individual child's best-interest

The "foundational" communitarian alternative

In the previous section we have illustrated that dogmatically upholding our liberal values in the case of disabled children's best-interest can have liabilities, yet that these liabilities occur most alarmingly in the case of profound retardation As such we argued that to categorically and thoughtlessly render liberal values invalid is not a desirable solution Both viewing disabled children as "identical" to their non-disabled peers as well as convicting them to the state of irrevocable "difference" is questionable As such the Deaf culture route has concrete advantages, yet in the encompassing way in which it is advocated it risks ending in the reverse

The advantages of Deaf culture have been verbalized in a variety of ways, and many of these arguments are likely legitimate to some extent Most importantly, Deaf culture certainly provides the best way for deaf children to access language, and as such may also be of considerable affective value Yet, what we are discussing here is how we should proceed with deaf children as they *mature* – more specifically in a time when cochlear implants are readily available Navigating on liberal childrearing values, we

suggested that – generally speaking - care becomes of lesser importance while autonomy to choose one's own life-path and have access to basic opportunities emerge as dominant values. In the previous paragraph we questioned if an encompassing care-ideology is a satisfactory legitimization for upholding care-values perpetually in the case of deaf children. Still, Deaf culture advocates often seem to argue that we should. They may be correct in their belief, yet we also argued that we feel that *if* we draw such a conclusion it should be based on a fair and honest appraisal of facts: as we argued, we see no *foundational* reasons to a priori withhold general liberal values to deaf children, and hence feel that "facts" must follow any appeal to do so nonetheless.

One reply to this position may be that Deaf culturalism does *not* result in an assault on deaf children's liberal values at all, but actually caters to deaf children's best-interest. While this certainly does not apply to the encompassing form of Deaf culturalism that we encountered in our empirical material, this does not necessarily mean that it is absent in Deaf culturalism as a political ideology as well. An important and previously discussed premise of this position is that deaf children, with or without an implant, will fail in the mainstream – which makes Deaf culture their most likely "prospected future". Another element that we discussed previously, was that the value of the lives of those deaf individuals that do succeed in the mainstream was minimalized, mostly in reference to their assumed negative self-esteem. Yet this latter appraisal can only follow from a comparison between the lives of those who live in Deaf culture and those who do not, and to fairly make such a comparison we need "facts" that we can gauge. However negative some Deaf culturalists may be about the lives of mainstreamed deaf adults, we lack the facts to underpin this appraisal. Yet even if we did have access to "facts", we would also need to agree on which facts are relevant and by which value-standard. In this chapter we have upheld a broad liberal perspective as a "foundational" value-standard. Yet even though this may represent our current dominant value-standard, other "foundational" standards are very much thinkable. Furthermore, and this is a crucial point, a different value-standard can have significant impact on how we would come to evaluate the "facts" of a mainstreamed life versus a Deaf culture life.

One crucial alternative value-set is provided by what is commonly known as "communitarianism". Deaf culturalism makes an appeal upon communitarianism. It asks us not only to look at the "facts" differently, but also asks us to look beyond our current political world: to be "visionaries" of possible alternative political realities. Though such a call risks falling victim to "revolutionary" utopianism, this in itself is an insufficient motive not to explore their avenues (Achterhuis 1998; Rorty 1998b). Still, it appears that it is a revolution that Lane seeks:

> What can a hearing person of goodwill do? Karl Marx said that the role of the bourgeois intelligentsia was to hasten the revolution. (Lane 1992, 87).

A prevalent approach to bring the advantages of Deaf culturalism to center-stage without risking falling victim to an encompassing "cannot do" axiom, has been to criticize the political landscape of society itself. Several "militant" communitarian authors choose to question our liberal social values fundamentally, to replenish them with a view that – coincidentally (most authors do not write about the disabled specifically, but present us with a much more global "society critique" instead) - accommodates the disabled more positively (Beauchamp 1989a; MacIntyre 1997; Sandel 1998; Kymlicka 1989; Watzer 1984). Somewhat similar to Schwartz, communitarians emphasize the paramount value of socio-cultural "belonging" and point out that a sense of "being connected" occurs in confined locality rather than society at large. The liberal view is criticized as viewing "autonomy" and "choice" too much from an individualist perspective (Beauchamp 1989a).

> In most American societies there is a strong tendency for people to be independent, self-sufficient and completely autonomous. Though America enjoys great benefits and fine positive qualities, in my opinion, there is a disturbing phenomenon, rapidly growing, which I call 'the psychosocial epidemic of individualism'. It is manifested by the increasing emphasis on personal privacy, autonomy and boundaries. These notions are glorified to the degree that they are becoming well established as social norms and moral virtues...(Abi-Hashem 1998)

Autonomy and community are intricately related, communitarians pledge. Many communitarian authors have depicted the situation of modern pluralist societies as consisting of several more or less distinct "micro-cultures" that only overlap partially in the macro-cultural domain, a position that has stirred a broad political-philosophical debate with liberal thinkers – who generally question if we should aim for such a "Scottish Kilt" model of society, for more or less the same reasons that we discussed in terms of the idea of foundational "difference" (Bank 1981; Appiah 1996; Rorty 1998b). While foundational difference can be of strategic value in dealing with the overt backwardness of specific oppressed minorities, to transform it into a foundational political philosophy is questioned: basically it seems because of disagreement with the moral legitimacy of the extreme egalitarianism in which it could result, but perhaps also because "the moral unity of humanity" is ultimately considered rather crucial to "fair" political states that nourish solidarity – though we add that this summary is *by far* to brief to cover the breath and depth of the debate that extends to many books and numerous articles (Appiah 1996; Rorty 1998b; Schlesinger 1993).

In either case it seems to be assumed that a communitarian value-standard will benefit Deaf people optimally, and give them an edge over peers who live in the mainstream. Deaf children from this perspective are rather similar in "value" to non-disabled children, so dodging our previously described sense of moral incoherence. Like hearing children they have their specific community in which they express their connectedness and identity: for deaf children this equates to Deaf culture (Lane 1997). It

is reasoned that Deaf culture will result in a viable social stage that in turn can allow the deaf room for self-fulfillment.

> Nor do we have any more concern with autonomy and independent living than people in general: DEAF people cherish interdependence with other DEAF people. (Lane 1997)

In a communitarian society that holds solidarity towards "difference" as a high virtue, Deaf people can be trained to serve Deaf culture. The establishment of deaf colleges and universities can guarantee high-level training for Deaf people, and can also serve as their base for professional life. Deaf psychologists and Deaf physicians can offer their services to the Deaf population in need. Yet such a segregationist view is not mandatory. The Deaf culture approach can also be seen as "optimizing" a deaf individual's cognitive skills to fit their individual talents, and as such he or she can be optimally prepared to succeed in realizing opportunities in mainstream society. While the communicative barrier remains or becomes larger by this policy and as such could obstruct a deaf person's actual access to mainstream opportunities, this could be circumvented by making an appeal on the necessity of solidarity towards "difference" or, if solidarity would fail, by appealing to disability acts and non-discriminative legislation, which can "force" deaf people into the workplace so to say and hence enforce equality.

While these political options are viable and a serious alternative route, they have distinct liabilities as we discussed in the previous section, liabilities that are rarely considered – something that is rather characteristic for utopian narratives (Achterhuis 1998). Firstly they represent a unilateral child-centered approach and make great compromises in their quest, as they potentially injure the parent-child relationship. After all, to make the utopian view work "optimally" would require that a deaf child is separated from his or her "unfavorable" hearing family early on. Secondly, they skip over the importance of scrutiny of the "facts" that we discussed before: the utopian view relies on theoretical or political assumptions that, as we argued in chapter one, have not been tested let alone proven convincingly, while such evidence is rather crucial (Buchanan 1989). Stewart comes to a similar conclusion:

> Arcane linguistic and cultural theories are being promoted concerning "the language of the deaf", "the culture of the deaf", and "the failure of deaf education", presented not as the pure speculations they are but as absolute facts to deaf people, their families, and the general public. (Stewart 1992).

While we cannot disprove utopian arguments based on empirical material either, we can present a dystopia in response – to reveal what the "purified ideal conceals" (Achterhuis 1998). The vast majority of information in our world is distributed in either the oral-aural or written form. While the cognitive development of deaf children may benefit from an exclusive Sign language environment – we will assume this for now - it remains to be seen if this edge will continue in adulthood. One could, for example, argue that a fortuned Deaf individual will slowly lose his edge in adulthood as he or she will be

unable to digest the vast amounts of knowledge that our society transmits in an oral-aural or written form. It is likely for this reason that many of today's bilingual programs emphasize reading and writing skills – yet some question exists whether reading and writing skills can develop optimally if the spoken mode of a language is not mastered (Paul 1993; Stewart 1998; Perfetti 2000). Regarding individual cognitive development a pragmatist would perhaps ask: what "use" does one have of an optimal cognitive development if one lacks the environment to express it in (Field 1998)? Laundy has stated that at least two language components should be distinguished in this context, namely language as a *tool of thought* and language as *oral language* (Laundy 1998). While the former is facilitated through schooling, the latter is facilitated mostly through interpersonal social contact. Children who attend bilingual deaf schools and who communicate mainly through Sign at home clearly lack the latter and may as such be expected to develop less oral language skills. Field's concept of literacy "range" for example would result in quite a different appraisal than more conventional definitions of literacy. For Field literacy range is the power that language skills provide in the larger world (Field 1998; Menzel 1998). High proficiency in Sign may thus equate to a rather low literacy range.

This dystopia argument becomes only more convincing if one does account for the vast uncertainties that we believe to be inherent to the Deaf-Deaf paradigm itself. Can the assumed benefits of Deaf-Deaf children be translated to deaf children of hearing parents without reserve? Is early enrollment in residential school in itself not a risk factor? Will an exclusive Sign strategy *really* result in more autonomous deaf individuals or will they rather encounter a coercive identity script? Instead one could argue that a self-contained Deaf culture is likely to result in Riesman's traditional man whose being is determined almost completely by the tradition of the community in which he lives, which seems at odds with our modern pluralist and dynamic society in which such single life plans are rather unfit (Riesman 1957; Appiah 1996). Indeed parents seemed to understand this. Providing their child with a strong identity would best be realized by submerging him or her in Deaf culture, yet the authoritarian character and content of Deaf culture, in which identity is "superimposed" as Fromm has said rather than found through "serene self-examination" in the words of Okri (Fromm 1994; Okri 1997; Appiah 1996), does not fulfill the ideal of the autonomous inner-directed man. Will culturally Deaf autonomous individuals *truly* not experience the agony that has been attributed to oral deaf people, and will they thus really become "happier" people? Will the communitarian and civil rights movement succeed and will they be lasting? Though this latter question is a rather weak reply, it is a comprehensible one in the context of parents who must actually deal with a concrete deaf child in our concrete present world – rather than a visionary world. All in all we feel that these potential liabilities and uncertainties amount to such heights that it seems preposterous to adopt the underlying philosophy as our main compass (Buchanan 1989). Beauchamp feels that one of the problems with utilitarianism is that it is inclined to "demand too much" or *maximize* if their perspective is too unilaterally set at "good consequences", thereby potentially overriding other important values

(Beauchamp 1989a). Critics feel that as such utilitarians "fail the test of practicability" and are at risk of becoming an "ethics of fantasy" (Beauchamp 1989a; Mackie 1977).

The core of the best-interest argument may be said to evolve around the philosophical-anthropological question concerning the nature of humanity, more specifically the disagreement between communitarian and liberal theories. Communitarian theorists commonly accentuate the social embedding of the individual. Most commonly, it is believed that a feeling of communion is beneficial to humanity in general and the oppressed in particular.

> However, if the economic, social and political conditions on which the whole process of human individuation depends, do not offer a basis for the realization of individuality in the sense just mentioned, while at the same time people have lost those ties which gave them security, this lag makes freedom an unbearable burden. (Fromm, 1994, 35)

Without such an embedding man would drift towards "moral aloneness" which is assumed intolerable (Fromm 1994). As Fromm reminds us, even Robinson Crusoe had the company of Friday (Fromm 1994). Under normal circumstances, communion or "togetherness" (Skolnick 1974) is provided by the "primary ties" of the biological family. Yet it may be argued that these primary ties are not restricted to the biological family per se. It is exactly this point that some Deaf culturalists have made: they have disjointed the goal of communion and belonging from the biological family and placed the former at the top of the agenda. What is considered essential is that deaf children have optimal access to a sense of communion and belonging, the context in which this is located is considered secondary. Furthermore, it is assumed that Deaf culture provides in this need much better than the natural family ever can. Yet as we stated, we do not feel that communitarian theory should fulfill the role of uncontested moral standard, certainly not if it leads to social circumstances with rather obvious liabilities as we feel is the case for radical Deaf culturalism. In principle the same is true for "radical" liberalism. Rather we feel that both provide a valuable space to rethink the concept of best-interest in a specific context and still is in debt of empirical scrutiny.

Parenting deaf children as an eclectic enterprise

So far we have drawn repeatedly on the example of the profoundly mentally retarded. The reason being that most in-depth studies on this subject have appeared in the context of mental retardation. Also, the case of profound mental retardation is illustrative since the assumption that our liberal values are inadequate seems almost intuitive: there simply may be no other way of thinking about the profoundly retarded than from a foundational perspective. Finally, it may be that the vast dominance of retardation literature in the field of child disability may co-explain the situation in the field of deafness. Yet, there are some distinct and highly relevant differences between mental retardation and

deafness. Some respondents actually alluded to the case of mental retardation: when they did it was mostly to point out one aspect that differentiates mental retardation from deafness, namely the *potential* of deaf children. One of the major complicating factors in the setting of a deaf child is that, unlike children with a cognitive disability, "permanence" is *not* a fixed entity - meaning that one can at least theoretically get a long way with such a child.

Through experience parents indeed learned that one deaf child can be very different from the next. By encountering other deaf children and monitoring development and by meeting adult deaf individuals, parents realized that the scope of future opportunities is very wide indeed. Parents became much more pragmatic in their orientation and dared to look beyond the outer limits of deaf ecology. Parents de-essentialized Deaf identity, much in the same way as Rattansi has advocated in the context of ethnicity (Rattansi 1995). The child him or herself was instrumental in this process, since the older child came to function as a benchmark of the claims by deaf ecology. Based on their knowledge of their child, his or her abilities and emotional resilience, parents became convinced that much more challenge was possible than suggested to be "good" by deaf schools. Having a grown child allows one to gauge one's actions directly: parents sought a maximum of challenge within the child's range of resilience. In doing so they developed a rather eclectic child-centered attitude.

> Utilizing diverse sources of knowledge, selecting from those sources the knowledge most useful to them. They make use of different vocabularies at different moments, speak different languages in their relation with different people. (Isarin 2002 – translation ccw)

As an alternative, parents seemed to promote a view that was rather similar to dominant child rearing ideology, be it not in an encompassing or ideological manner. Parents firmly disagreed that liberal values should be categorically excluded from the lives of their children. They also rejected the communitarian-based inflation of the socio-emotional and the advocacy of a "special" socio-cultural stage. One of the ways in which this seemed to be realized was by "normalization" through deconstructing the concept of autonomy (Reinders 2000). There is not one single way of perceiving autonomy parents seem to argue, rather they perceive it as a continuum, much like the concept of competency in medical ethics (Musschenga 1987). Hence, autonomy as a generic and highly theoretical concept is replaced by a closer-to-life heterogeneous model. One can also act autonomous by choosing a bite from a lunchroom card, by choosing friends, by choosing where to live without interference etcetera. What results is sort of a phased, contextual or scale-like concept of autonomy rather than a utopist focus on optimal outcome and "ideal" humanhood, that seems almost inherent to the communitarian view discussed above (Musschenga 1987). According to Buchanan, demanding that parents realize the optimum situation for their children is preposterous (Buchanan 1989).

> To treat the best interest principle as a literal and absolute commandment, rather than as a guidance principle, would be to impose morally excessive and indeed impossible demands upon any decision-maker...(Buchanan 1989, 259).

Such demands are unrealistic in conceptual terms (what is an "optimal" outcome?), insensitive to the reciprocal relationship between our heterogeneous values (inclined to focus on either guardian or gardening values), too unilaterally based on a self-sacrificing child-centered perspective as well as the cradle of far-reaching and encompassing plans that are likely to produce considerable liabilities in their way.

> Even today it is people who consistently speak of "developing of man" and "attaining an optimum of happiness" who proceed to make the most far-reaching plans for a panoptic society. (Achterhuis 1980 – translation ccw)

Parents were at odds with the care-ideology that dominated the institutional setting and they have been ever since the mid 1950s. Parents spoke of "conflict" when they described their relationship with signing deaf school, in particular parents of older children did. The origin of this conflict was about their role as a parent on the one hand, but it was also about the pervasive care-environment at deaf schools. Parents first and foremost resented the nursery climate at deaf schools. As a part of that they resent the low-challenging environment at these schools, the way spoken language was ignored and the way mainstreaming was not even considered an option. This has led to the situation where "deconcentration" has become a goal in the management of people with a disability. Deconcentration implies de-institutionalization. It also implies the release of care-ideology, expressed by the motto of this process in the Netherlands: "de perken te buiten" ("beyond the garden") (Reinders 2000).

Conclusions

Two ideologies can be identified in the debate surrounding deaf children's best-interest. On the one hand, we find Deaf culture as an omnipresent ideology. As we discussed, it departs from a foundational discourse that essentializes deafness as a "distinct people" in cultural and identity terms. We have continued to show that in a best-interest context, this translates to a view on deaf children as children with a predetermined "life-plan" and a fixed "prospective future". These children, can only become what they "already are" – namely Deaf. Beyond a foundational debate that evolves around "cultural geneticism", this position seems to be led by "strategic pragmatism" really. It is a priori assumed that deaf children "cannot do", and that if we challenge them nonetheless, this will certainly harm their self-esteem. On the other hand – and diametrically opposed to Deaf culturalism - we find radical liberal ideology, which would perhaps a priori consider deaf children as "normal children". Such a view upholds the values of "liberty" and

"opportunity" rather stringently. Deaf children as such, become normal children for whom we should – before anything else - safeguard choices and opportunities.

In the case of profound retardation, a foundational discourse of difference and care seems the only reasonable position we can take. To talk about "liberty" and "opportunity" is rather unfit to their case. Yet this is much less true in the case of deafness. Deaf children are *not* defined by their deafness, the way that profoundly retarded children are. To assume that a deaf child can only become what he or she "is", seems rather preposterous, which implies that a foundational care-discourse is rather inappropriate. Yet to assume that deaf children are infinitely free in what they can become is as unreasonable in the context of deafness as it is in the context of parenting in general. People are limited by virtue of their social background, the culture they live in and their talents – hence depicting the inappropriateness of radical liberalism in general really. More or less the same is true for deaf children. They too are defined by their freedom, but their limitations as well. As such the choices we create for them are "possible" choices, the life-plan we envision "possible" life-plans at best. Rearing children in general, and rearing deaf children in particular, hence becomes a matter of seeking a fair balance that is likely to be a rather eclectic activity.

The concept of self-esteem, so central in disability literature in general, seems to assume that self-esteem can only flourish if we respect the "self", and as such seems to appeal to the notion of the self as a foundational given. In this context it thus appeals to the image of the deaf as children that "cannot do". To challenge them to do what they "intrinsically" cannot, will likely injure their sense of self. If we abandon that premise, the ground for questioning self-esteem evaporates. Parents do not disagree with deaf schools in terms of the value of self-esteem itself, yet differ in their view on the "self" of deaf children. Contrary to deaf schools, they believe that deaf children are *not* defined by their deafness and can be challenged beyond it. Challenge in itself is not a source of low self-esteem, unless its goals cannot be realized. Parents feel that they *can* be realized, but not as blindly as a radical liberal theory would suggest. They do not see the future of their children as one of boundless opportunity, but one of "possible" opportunity.

If we define Deaf culturalism in terms of a child's best-interest, "acceptance" remains an important issue. We previously discussed this in terms of the extended pragmatic concern over deaf children's socio-emotional well-being if deaf ecology's prescriptions are ignored. Parents have to "accept" that their child is different from other children and that this difference may demand different choices, namely choices that are in agreement with the realistic capacities of a particular child. From a pragmatic point of view it is undeniably true that disabled children do have specific limitations and that trying to overcome them might be futile as well as potentially harming. This illustrates that the dichotomy between the "what" and the "who" is artificial to some extent. If the "what" is separated from the "who" too blindly and parents come to focus on minimizing the impact of the "what" too ruthlessly, the child will likely suffer. However, ultimately

the legitimization is not a matter of moral character per se, but primarily empirical since it relies on a specific "facts" vis-à-vis the "capacities" of deaf children (Hays 1996). Thus, the question boils down to what the "realistic capacities" and "limitations" of deaf children are precisely? Robinson suggests the following vis-à-vis retarded children:

> Acceptance of a retarded child involves warm appreciation of his individuality, pride in his assets and tolerance of his shortcomings. (Robinson 1965; Gresnight 1973)

Yet what are these "shortcomings" of which Robinson speaks? One of the main factors that complicate this issue in the context of deaf children is the lack of an unambiguous framework of capacities and limitations as compared to for example the case of the child with a profound mental disability. As we have stated, coping theory plays a dubious role here. It has been common practice in deaf studies to speak in terms of coping theory and thereby define "well-adapted" and "badly-adapted" parents. Well-adapted parents are said to be parents who accept the permanency of the condition (Hejblum 1982; Bodner 1986; Vernon 1984). Yet what is often missing from these theories is a detailed description of "what" this permanent condition constitutes of really.

Parents appeared to conclude that this silence is commonly misused in the sense that it is filled with deceptive arguments. Parents felt that deaf ecology's prescriptions were arbitrary to some extent and represent choices or preferences. From this experience parents deduce that there is no rigorous universal moral axiom dictating acceptance of the "condition" as presented by deaf institutes. Parents realized this and questioned the empirical premises of this claim. Parents felt that the empirical suggestion of vulnerability was deceitful in the case of their individual child. Larson has described a similar trend in parents of children with a cognitive disability (Larson 1998). As we mentioned previously, these parents too are confronted with a highly uniform and pessimistic view on the child's perspective: not much is to be hoped for. Yet, in quite a few cases the development of a child exceeds these negative expectations, which leads parents to become somewhat skeptic about the forecasts made by professionals (Larson 1998).

It could be that parents estimate the potential of their child unrealistically high. As O'Neill has pointed out, while parents are granted the right to decide for their children, they are not unrestrained in this right: "their decisions must also reflect some judgment about the feasibility of their project" (O'Neill 1979). She further comments that:

> It is, of course, hard to know exactly what the minimal requirements for child rearing in a given society are; hard to foresee one's own capacities and situation over a long stretch of life; and impossible to foretell what difficulties a particular child may bring. Even so, it is not difficult to identify some situations, such as serious ill health or abysmal poverty or distaste for children, which, if there are no available alternative arrangements for the child's rearing, would make a decision...unreasonable. (O'Neill 1979, 29)

Hence, parents may be expected to have seriously thought over their decisions and strategies: its assumed effect on their child's well-being, his or her autonomy potential but also the practical feasibility. If the signs of failure mount, it reasonably becomes senseless to insist on guardian values. Indeed van den Boer states that the estimated feasibility of goals of gardeningship and guardianship are a strong factor in predicting decision-making (van den Boer 1997). It seems that it is exactly this that parents were doing. Parents of older children are faced with a "fixed" reality. Their child has lost the potential for change, which makes any aim towards change rather senseless. As a result they have to make the best of the opportunities that are available. This is not to say that they come to value Deaf discourse over mainstream discourse, but rather that they work at the first because the second is not available. Yet it could also be that deaf school personnel is embellishing the "exceptional needs" of deaf children. Such a risk has been discussed in the context of other care relationships (Collier 1983).

In an apparent attempt to relativize liberalism, Csikszentmihalyi states that liberal values such as autonomy are only important to us because "we think that they will make us happy" (Csikszentmihalyi 1999). And who is to say that the autonomous, well-developed and socially vibrant individual is actually happy? Is happiness not rather found in the informal environment of friends and family? Opposed to the "monopoly of materialism" some critics have placed what is referred to as "communitarian" values (Csikszentmihalyi 1999). It is indeed unlikely that the two values can be equated as perhaps has been assumed. Reaching a high level of autonomy, a respectable education and career are no guarantees that happiness will follow. It is likely that some degree of autonomy or "material well-being" is a prerequisite for happiness or "subjective well-being" to be experienced, yet that does not make autonomy a linear proxy for happiness. In words of Csikszentmihalyi:

> Although cross-national comparisons show a reasonable correlation between the wealth of a country as measured by its gross national product and the self-reported happiness of its inhabitants (Inglehart, 1990), the relationship is far from perfect. The inhabitants of Germany and Japan, for instance, nations with more than twice the gross national product of Ireland, report much lower levels of happiness. (Csikszentmihalyi 1999).

Yet to discard of liberal values based on the lack of evidence linking it to happiness in a linear way seems preposterous. Developing countries that lack autonomy are likely to strive for autonomy first and happiness second. To ignore this fact and to make happiness a priori override autonomy is to convict these nations to their state of dependency. Many refugees leave their poor countries to seek possibilities for autonomy and material well-being in the West. Those who feel that happiness can only thrive in "cultural authenticity" and should override the quest for autonomy and economic fairness may conclude that refugees should repatriate instead as some indeed have (Rattansi 1995). Indeed Rorty argues that while "socially accepted sadism [towards ethnic minorities – ccw] has steadily diminished, economic inequality and economic insecurity have steadily increased" (Rorty 1998b). Hence, to deny autonomy fully is not only to deny a cardinal

human value independent of happiness but also to deny a likely prerequisite for happiness, the interdependence of these factors should be recognized in our liberal society (Musschenga 1987) As liberal thinkers such as Buchanan and Brock assert, being able to set one's own course in life, ought to be perceived as virtuous in terms of contributing to well-being in broader terms than "happiness" suggests (Buchanan 1989) Csikszentmihalyi also supports this view

> There is no intrinsic reason why these two sets of rewards—the material and the socioemotional—should be mutually exclusive (Csikszentmihalyi 1999)

In the case of this study we encountered a similar situation as "guardian" and "gardening" perspectives were pitched opposed to each other While this may be the case in "normal" pedagogy as well, in the context of disability it occurs more ferociously On the one hand stand classic liberal values such as autonomy and self-reliance while on the other we see the demand of belonging, socio-emotional well-being and happiness The first implies a challenge and confrontation with disability, while the latter is assumed to blossom in absence of these factors Self-esteem is a key concept in this regard Indeed as Hays has argued this is a strong ingredient of popular parenting ideology

> When a mother does talk about her hopes for her child's future success, she makes it very clear that this has nothing to do with the child's monetary success and everything with his or her future happiness [ ] The moral lesson here is that the person who is "rich" is not the person with money but the person who is kind, considerate, and generous and has formed close, long-lasting relationships (Hays 1996, 124/127)

Yet, the peculiar thing about this statement is that it seems to consider material and immaterial well-being as two completely separated categories A somewhat similar move is also encountered when the concept of Self-esteem is introduced in the context of the disabled it is assumed that there is only one way to establish self-esteem, namely by recognizing the "self" as an authentic given Challenging a child is as such considered of potential harm to his or her self-esteem This is a questionable portrayal however Challenge can be a source of positive self-esteem, if not now then perhaps in the future This does depend of course on the reasonability of the task if the task is impossible, it is likely to injure self-esteem Thus, this issue also evolves around the idea what deaf children can and what they cannot do Hence, we should be careful that a call for self-esteem conceals a rather embellished view on deaf children

Yet, we feel that it makes little sense to polarize and speak of an ideological clash, at least if we come to focus pragmatically on deaf children's best-interest

> Political debate at high levels of abstraction is, typically, debate between competing idealizations, and thus between competing visions of the utopian future of our community (Rorty 1996)

We should perceive of guardianship and gardeningship as two narratives that both represent meaningful cultural child rearing values and which most parents will have incorporated to some degree (Taylor 1995). Both should be incorporated in the appraisal of best-interest in the case of deaf children. Indeed Buchanan and Brock define "interest" both in terms of "opportunity" or "open future" interests as well as "socio-emotional" and "human relationship" interests (Buchanan 1989; Feinberg 1980).

The nature of children's interests (Adapted from Buchanan 1989)

- Current interests
  - Socio-emotional or "experiential" interests
  - Human relations interests
- Forward-looking or "open future" interests
  - Opportunity interests
  - Human relations interests
  - Experiential interests

Current experiential interests denote that a child has the right not to suffer unreasonably. While some degree of suffering may be warranted to safeguard a child's forward-looking interests, we must be informed about the intensity of the injury, about a child's resilience to deal as well as what benefits are to be expected. Current human relationships interests, imply that we ought to safeguard a child's access to a loving and caring environment, to friendships and intimacy – not only in the future but in the present as well. Forward-looking interests, which Buchanan feels should mostly override in the case of child-advocacy, comply mostly with what we discussed in terms of liberal child advocacy, though they are clearly replenished by communitarian-oriented values. Opportunity interests refer to the need to enjoy basic opportunities such as an education, which are required for a person to choose their life-path self-determinatively. Future human relation interests are more closely related to communitarianism, in the sense that it underscores people's future need for love, friendship and intimacy – in addition to opportunities – and our duty to make sure that we provide them appropriately to fill this need. Future experiential interests finally, refer to a child's right to a future without severe experiential grief or pain.

Hence, the communitarian discourse cannot simply be discarded. While in its "militant" form it may be said to support an encompassing care-ideology, it is unlikely that this has been the intention from the outset for the more "moderate" communitarians. Rather "moderate" communitarianism points out the very real and relevant limits and liabilities of extreme liberalism and provide a basis to replenish liberal values: socio-cultural context (friendship, love, intimacy, ties of loyalty and caring) is at least as essential to a child's best-interest as individual autonomy (Buchanan 1989; Taylor 1995; Beauchamp 1989a). As Gutmann states:

> Do most people need a secure cultural context to give meaning and guidance to their choices in life? If so, then a secure cultural context also ranks among the primary good,

> basic to most people's prospects for living what they can identify as a good life (Gutmann 1994, 5)

Beauchamp convicts "militant" communitarians of falsely assuming a moral dichotomy of "community or autonomy" (Beauchamp 1989a) The communitarian critique becomes only more relevant in the case of the disabled, the case of the deaf being rather exemplary in this context While it is rather clear to see how radical liberalism poses the profoundly mentally disabled for a significant problem, which likely explains the fact that communitarian values are encountered frequently in this context, this is not necessarily the case for the deaf or at least not as violently, though the exact appraisal will be dependent on the individual child Hence, the case of the deaf challenges us beyond the classic rhetoric between the two extreme ideologies Liberal values are not a priori unattainable in the case of the deaf, yet blindly aiming at these values stands a significant risk of sacrificing the values that communitarianism has confronted us with As Gutmann claims, the extreme liberal view "underestimates the need of people as members of discrete ethnic, linguistic, and other cultural groups for public recognition and preservation of their particular cultural identities" (Gutmann 1994) The case of the "successful" oral deaf illustrates that reasonable spoken language skills and high educational standards do not *guarantee* that deaf individuals will integrate smoothly in hearing society in both its social and societal spheres (Van Noort 1999) Skilled deaf individuals sometimes still encounter difficulties to find jobs that fit their talents and educational achievements In addition, even more significant problems are encountered in the social sphere As a result of the latter, some successful deaf adults state that they continue to value the socializing opportunities that deaf peers provide Communication with deaf peers is smooth and often more reciprocal as compared to hearing peers (Van Noort 1999) The fact that some deaf individuals attest that they had "retreated" to Deaf culture, illustrates that the problems that are encountered should not be taken lightly as they apparently can lead to disillusion and skepticism Deaf culture critic Bertling also underscores the importance of deaf peers and Sign language to many deaf people

> The ability to have unrestricted communication at least with some people, is necessary sometimes to preserve sanity and prevent feelings of isolation (Bertling 1994)

The case of "successful" deaf adults becomes even more alarming if we consider that, at least before the introduction of cochlear implants, they represent a small minority of all deaf individuals, hence challenging the notion of feasibility Be it the result of a lack of a sound education or a lack of intrinsic capacities, the vast majority of profoundly deaf individuals fails to master a reasonable level of spoken language proficiency It follows that retreat into Deaf culture is a lot that cannot be shunned reasonably for many deaf adults As we argued, it is this empirical reality that has likely triggered modern day Deaf culture ideology to rise to the forefront Still, successful deaf adults also depict the consequences of the special and segregated status attributed the deaf in the Deaf culture view These adults remained interested in and actively aimed at participating in hearing

society, a finding that is in agreement with Appiah's general critique on a politics of recognition (van Noort 1999, Appiah 1996)

Yet from this study the suggestion seems appropriate that, aside from the positive impact in social terms, Deaf ideology invokes distinct uncertainties and rather serious liabilities as well Deaf ideology seems to have become an *axiomatic narrative* that has lost contact with the problems that it was meant to answer or "counter" and has instead developed into an encompassing and homogenizing meta-narrative that has rendered dominant liberal values offside in a rather fundamental way (Gutmann 1994) Preoccupied with its own ideological battle, Deaf ideology is at risk of curtailing the opportunity to function in hearing society and nullify individual opportunity at the root by advocating that deaf people *ought* to be true to themselves only (Appiah 1996) Though we should be careful to draw conclusions on this to easily, anecdotal information by successful deaf adults reveals that they are often not overly positive about the space Deaf culture provides for self-development Bertling also supports this view

> Sadly, in the deaf community one is more apt to be engaged in a conversation on how to get more services and "benefits", than any discussion on becoming self-sustaining or how one can become a contributor to society (Bertling 1994, 93)

In our opinion, speech is a prerequisite to function socially in hearing society To outcast the opportunity for speech based on the axiom of Deaf culturalism therefore implies to outcast the opportunity to choose one's life path autonomously Indeed authors such as Bertling have warned against the practical consequences of deaf school education

> I run into many culturally-deaf adults today who have a much better hearing ability than mine, yet cannot speak, never learned to speak or simply stopped speaking While individual responsibility can take some blame, the state residential schools must assume some of the responsibility for this Parents of deaf children need to be aware of this ominous reality If your small child has any hearing ability at all (not being totally or profoundly deaf), placing a child into this type of school is questionable and probably should be avoided at all cost (Bertling 1994, 31)

Now some may argue that liberal values will not materialize or yield too great liabilities We feel that this has not been proven beyond reasonable doubt and therefore does not justify the categorical exclusion that we encountered (Buchanan 1989) Others may argue that the political Deaf culture movement allows the deaf not only optimal opportunities for social functioning but ultimately maximal opportunities for the realization of liberal values as well We have argued that this assumption is culprit of ignoring the liabilities that such an "optimizing" strategy would entail while its convincingness is rather fragile Furthermore, the pragmatic fact that deaf schools are failing to realize liberal values even within their own discursive context, evident from the global low-challenging climate at signing schools, seems to illustrate that the promise of optimal outcome is failing and rather that care is now taken as an axiom (Alden 2001)

As deaf education stands today, it is preparing deaf children for comfortable social lives primarily. It is this issue that all parents depicted, independent of their language preference (Bertling 1994). It is this issue that connects all parents rather than separating them over issues such as Sign language versus spoken language. As Bertling puts it, the deaf school experience is meant to "convert" students to "the Deaf culture's way of life" (Bertling 1994). This "conversion" may be compared to Taylor's view on bilingualism. Commenting on the Canadian francophone debate he states:

> It is not just a matter of having French language available for those who might choose it. This might be seen to be the goal of some of the measures of federal bilingualism over the last twenty years. But it also involves making sure that there is a community of people here in the future that will want to avail itself of the opportunity to use the French language. Policies aimed at survival actively seek to create members of the community, for instance, in their assuring that future generations continue to identify as French-speakers. There is no way that these policies could be seen as just providing a facility to already existing people. (Taylor 1994a, 58-59)

In sum the "moderate" communitarian view provides a rich and valuable counter-narrative to an exclusionary liberal perspective, a situation that is magnified in the case of the disabled in general and the deaf in particular. It underscores the importance of social functioning and the interdependence between social and individual values. Based on the narratives of adult deaf individuals it leads to the conclusion that an exclusionary or radical liberal perspective on deafness has serious risks that we should contemplate when considering the best-interest of deaf children. Both the "material extreme" of liberalism as well as the "spiritual extreme" of communitarianism are likely to yield considerable liabilities (Csikszentmihalyi 1999: Beauchamp 1989a). The first may be argued to be represented by "oralism" mostly, while the second is represented rather strongly by "manualism" or care-ideology. Oralism may be argued to ignore the value of happiness, socio-cultural belonging and reciprocity in its blind aim towards integration. What seems to be the case in the reasoning of radical Deaf culturalists on the other hand is both a one-sided upholding of the value of happiness as well as the belief that deaf people will never be able to realize material goals or happiness in hearing society, which will leave them unacceptably disappointed and unhappy as a result. One way out is to "teach people to give up desires altogether and thus avoid disappointment" (Csikszentmihalyi 1999). While it is not so much of an ethical problem if unhappy adults seek to achieve such a state, is does become rather questionable if a program is a priori set up to systematically achieve the above mentioned goal in children or future generations in general. As such it appears an unreasonable response to withdraw deaf children from society all together.

Our material clearly illustrated that parents struggled with this issue, implying that they lacked an ideology of their own. On the one hand, parents will likely adhere to a gardening or "caretaker" perspective on child rearing by expressing the wish to safeguard emotional well-being and prepare their children for a fulfilling social life (Archard 1993). On the other hand, parents are likely to adhere to the dominant liberal perspective on

child rearing, which stresses the need to give the individual child an "open future" While the disagreement between parents and institutes centered on care-ideology, it also proved that parents were not insensitive to the *specific* arguments encapsulated in care-ideology What they opposed was the transformation of these values into an ideology, into an authoritative model (Taylor 1995) As such parents experienced a dilemma they were sympathetic to the specific arguments yet disagreed with the way they were implemented One of the main factors that contributed to the sense of dilemma that parents experienced vis-a-vis deaf school's care-ideology was that it is inclined to equal "happiness" to the "moral good" much more outspokenly as compared to non-disabled children (Callahan 1994) While aiming more and more for guardianship values such as self-reliance, parents had trouble placing the dominant value of happiness within these goals, something that was fuelled by DC-ID arguments and accounts of unhappiness of the adult deaf population Jaehnig has found a similar phenomenon in the case of children with a disability and speaks of the "double bind" in which parents are caught

> If parents keep the child at home they endanger their mental stability or the development of other children, if they seek residential care they are rejecting the child, if they try to stimulate him, they fail to accept the reality of the handicap, if they cater to his whims they contribute to his dependence they have no description of acceptable behavior and any action they take puts them in the position of needing the social worker's ministration (Jaehnig 1974, 77, Philp & Duckworth 1982, 40-41)

Thus, parents are caught between normalizing and stigmatizing ideologies Charging to get the most out of a child's capacity stands the risk of overstraining the child, of over-demanding and of accusations of non-acceptance Focusing on Deaf ideology one-sidedly implies that one underscores societies prejudices on deafness instead Charges of resigned coping, overprotection and romanticizing may rise in this context Yet in principle what these parents experienced is rather inherent to parenting in general Flacks describes modern parenthood as inevitably surrounded by confusion One of the points of confusion that Flacks depicts is the tension between "effort and indulgence" (Flacks 1974) Parents stimulate their children from a guardian perspective

> Typical middle class parents expect their offspring to strive and achieve and to understand the necessity for self-discipline and effort in attaining goals (Flacks 1974, 353)

Yet at the same time, they are inclined to indulge

> Indeed, in many families, parents indulge their children in order to demonstrate their love and care (Flacks 1974, 353)

Jacobs also notes that parenting is always a balance between gardenership and guardianship Parents want their children to be happy, kind and witty and to sustain a deep emotional bond with them Yet, parents also want children to fare well, not only

today but also after their time has past, which will to some degree imply that a child will have to release him or herself from the parent (Jacobs 1993b).

In our view, this state of confusion is amplified in the relation between parent and handicapped child. The mediating factor is the excessive sense of vulnerability that we described as well as the fear of being "brought to charge" by the child later in life. It is our belief that some parents, perhaps not our respondents, will experience a strong sense of confusion in demanding anything from their child really and that the degree to which this occurs has predictive value on how parents will stipulate their pedagogical course. It almost seems like a conflict between ratio and emotions in the sense that parents "know" that they should take certain action to promote their child's opportunities later in life, yet "feel" inadequate or unloving if they do so. Birenbaum feels that a "balance" between an attitude of normalcy while recognizing a child's concrete inabilities is the most nuanced of attitudes (Birenbaum 1970; Philp & Duckworth 1982). Ignoring the disability and over identifying with it being the two more extreme mechanisms. Even though parents appeared to attempt to silence their moral ambiguity most all admitted to it by stating that there would be a conceivable scenario in which they would have acted differently (Boyd 1997). If autonomy is estimated to be impracticable, such as in the case of severely mentally retarded children, parents are likely to adhere lastingly to the goal of well-being (Larson 1998).

What we discussed in this section implies several things. Firstly it leads to a support of the political effort, aimed to expand the opportunities of deaf individuals to enjoy education and participate in the work place. Secondly it implies that we should temper our hopes that oral skills will normalize the social lives of people with a hearing disability, which implies scrutiny when considering mainstreaming goals. The ecology of the deaf is valuable to many deaf individuals, including to some that have succeeded in mastering spoken language skills. As such the opportunities to engage in this social context should not be discarded to easily, even if it implies some compromise in terms of spoken language proficiency. Furthermore, we would do well to change our perspective to an eclectic child-centered one, implying that we should not choose for one *or* the other but rather a mix of one *and* the others tailored to the context of an individual child. We see no reason to exclude dominant liberal values from the lives of deaf individuals categorically. This implies that a care-ideology has no axiomatic place in the education of deaf children. As Dutch deaf educator Van Der Lem also holds, deaf children need to be challenged as much as we challenge our hearing children (Hiddinga 1999).

DECONSTRUCTING DC-ID AND RE-SETTING THE MORAL SPACE

Given what we discussed in this chapter one may question if DC-ID is not much more "intentional" and "conscious" than the concept of discourse suggests and represents an "ideology" instead We mention however that some have contested the distinction between discourse and ideology and that indeed ultimately the difference is difficult to make (Plamenatz 1971) While ideology may be argued to be a subset or a specific form of discourse, the concept goes beyond the definition of discourse While discourse is an anonymous and perhaps even subliminal structure, ideology is usually not Much more so than discourse, ideology represents a doctrine, a unity of ideas, ideals, passions, values and standards that are characteristic for a specific group and which may or may not function as justification of specific interests (Plamenatz 1971) Plamenatz refers to the most comprehensive form of ideology as a "total ideology" or "Weltanschauung" (Plamenatz 1971) It is an omnipotent system of thought that unites and connects a wide array of phenomena into its system of thought and counteracts contradictions Empiricism, conjectures and refutations are unlikely a part of ideology since what it serves mainly is a socio-political interest Departing from these definitions it appears that ideology may indeed be at stake in DC-ID If we focus on the writings of spokespersons of the Deaf world such as Lane and analyze the tenor of Deaf advocacy, this suggestion becomes even stronger Yet what drives this ideology remains rather fuzzy Is the cultural claim *genuinely* ideological or is it to conceal more pragmatic concerns? Is the case of the Deaf population *genuinely* believed to be analogous to ethnic minorities or is this ideology being employed because of its power to convince? It is difficult if not impossible to answer this question in this context Not in the last place because the argumentative structure of the minority debate in itself is rather heterogeneous and does not allow the extraction of straightforward ideological premises Perhaps this is because what works is the rhetoric basis of the minority discourse intellectual explicitness of ideological premises is likely to provoke academic debate rather than the civil action that is sought The Deaf are a (ethnic) minority and therefore their position is to be respected Acknowledging Sign language from this perspective may be considered an element of a "politics of recognition" (Taylor 1994a) Yet this sort of glorification in the name of recognition is not without hazards as some anthropologists have come to see (Friedlander 1975) Hence, as long as society does not change its attitude towards minorities, asking minorities to act out their distinctiveness is likely to harm them rather than providing relief from their precarious position Isaiah Berlin formulated this point as follows

> It is true that to offer political rights, or safeguard against intervention by the state, to men who are half-naked, illiterate, underfed, and diseased is to mock their condition, they need medical help or education before they can understand, or make use of, an increase in their freedom What is freedom to those who cannot make use of it? Without adequate conditions for the use of freedom, what is the value of freedom? (Berlin 1969, 124)

This is particularly true if the attributes of distinctiveness are rather incompatible with the values of dominant society as we discussed in the context of American education ("acting white"). Certainly, "not speaking" is such an attribute.

Today it seems that the practical implications of the Deaf culture discourse have been rather negative. It has resulted in a one-sided care-ideology that places the deaf outside the normal order rather irrevocably. Deaf children are instructed in Sign language, but the school climate insists on a low challenging environment as well. Moreover, the civil rights discourse has for now been unable to realize the resources (education, translators) needed to make things work. Yet even if these goals would be realized in the future, liabilities remain since to make things work the deaf would likely become rather isolated in their distinctiveness, both from intimate others (parents) as well as society at large. For the deaf this isolation amounts to even higher levels than in ethnic minorities (Appiah 1995; Taylor 1995; Silvers 1999). Isolation from parents and family is likely physical and profound since deaf residential schools are promoted as the ideal place for Deaf identity to flourish. Isolation from society at large is also likely to be profound, since many Deaf advocates practically ban spoken language.

Though it appears that deaf ecology operates a distinct ideology, one parent argued along a different route. CO1 believed that it was not so much ideology that explained the dominance of certain ideas in deaf ecology, but rather "indolence" and "habit". Low challenge, Sign language and a lack of objectives were portrayed as the "easy way" to go. Rising above that level, providing an individual challenging program was depicted as beyond the abilities of deaf school personnel. Deaf school personnel were also portrayed as "civil servants" in terms of mentality (C7a). Hence, deaf schools are depicted to defend their program not because they believe it is the best possible for deaf children but because of the lack of resources to imagine and implement a genuinely challenging environment. Yet this representation is perhaps even more threatening, since no one is accountable in such a system really. If the thoughts that reigned deaf ecology were ideological in content one could at least instigate dialogue. If the only explanation for dominant ideas is the system itself, such discussion is likely rather remote. Hence, in practice is may be that ideology is not the primary issue. Rather, as we argued, ideology is employed to maintain a specific practice. From this perspective, parents who claim their children are a factor that needs to be "dealt" with. This view may be congruent with the depiction of research into parents as an "institutional answer" to uphold authority.

The fact that teachers, counselors and Deaf adults are able to impact parents so much is likely multi-factorial in origin. Firstly, the authority gap is much larger in the case of deafness as compared to a hearing child. Secondly the future outlook of a deaf child is seriously compromised and as such the impact of education on this situation is great indeed, at least in theoretical terms. This situation "primes" parents to listen so to say. At least theoretically DC-ID can have significant impact on parents due to the "moral space" that it moves in: it homes-in on the moral concept of the Good parent, on

rather powerful standards of good parenthood. The Good parent is a child-centered parent foremost, a parent who places the emotional well-being of his children above all. Exposing a child to the difficult task of spoken language or a stigmatizing hearing environment is in potential conflict with this value The Good parent is one who experiences unconditional love Aiming to teach a child spoken language may be perceived as a sign of inadequacy Frank disappointment and unresolved grievance may be perceived as more explicit expressions of a failure to love one's child unconditionally The Good parent is also a tolerant parent, implying that he or she will treasure the child's unique identity rather than try to mold him or her conforming to parents' standards (Blokker 2000). The Good parent argument appeals to parents' moral self-image A choice that is incongruent with Deaf ideology is cast as proof of bad "moral character" so to say, an attribute that most people would like to avoid. From the above it appears that the logical equation becomes as follows: if one is a good and dedicated parent one naturally experiences love and affection towards a deaf child, which will manifest itself through concrete actions and decisions It appears however that especially this last step lacks the authority that it assumes. In fact what appears to happen here is that what is in core an empirical claim is linked to a moral claim, which renders testing of the former obsolete (Hare 1988) This maneuver is not unique to deafness, quite the contrary many authors have depicted it in our modern child-rearing climate (Eyer 1996). In itself this is not much of a surprise. If being a good and dedicated parent becomes a leading moral value in our society, individuals may develop a need for visible symbolic expressions of such an "invisible" moral or virtuous attitude. Yet, the construct does imply the inherent risk of transgressing the boundaries of the reasonable, of developing grotesque features, of developing into a social vigilation system even A concept as unconditional love is such an example: it needs no argument or explanation but seems to rely on moral intuition primarily through the postulate of the Good Mother, which Eyer compares to a "religious icon". Empirical evidence is mostly lacking however, which seems to suggest that empirical arguments are employed to muffle the gap that a sheer moral argument induces, paraphrasing Eyer:

> One of the reasons mothers take their advisers so seriously is that the advisers draw upon science. And we assume that science is a rational operation that yields facts we can rely upon [ ] the science on which these notions are based is about as reliable as those old wives' tales the experts love to warn us about (Eyer 1996, 69)

Acceptance appears, as we argued before, to be a "blanket term" used intensively by health professionals yet inadequately reflected upon (Larson 1998) Thus, besides learning what is "the right thing to do" with regards to the deaf child, parents learn what is "the right attitude to adopt". Goffman has described a similar moral system of reprimand

> The character of the stigmatized in the eyes of professionals is dependent on his relation to companions in misfortune, when he joins them he is «loyal» and a «true» individual, when

> he turns away from his own group he is a «coward» and a «fool». (Goffman 1963, 114 - translation ccw)

General studies on child-rearing determinants have clearly demonstrated that parental decision-making is a complex matter involving interrelated cultural, social, parental, child and local contexts. As we discussed, deaf literature has focused mostly on so called "stable parental characteristics" (Bronfenbrenner 1989). The choice of a language of instruction and an educational setting has been pervasively framed in the context of parents' "attitude" and "coping style" (Kohn 1963; Hoff-Ginsberg 1995). It is crucial to notice however that this assumption is not neutral from a moral or ethical perspective; rather it predefines the "moral space" in which the deaf educational debate it set. Many studies that have appeared in the field of deafness have been cross-sectional and provide no time-differentiation. The fact that no time-differentiation is made provides an important clew about the interpretational frame of these studies. It is evidently not the lack of knowledge or hands-on contextual experience that is thought to explain why parents feel what they feel, perceive what they perceive and ultimately do what they do. After all, knowledge and experience change over time and as such would logically demand time differentiation (Bruce 1994). Rather, the determining factor appears to be one that is independent of context, time, experience and knowledge: "attitude" fits this description perfectly (Fromm 1994; Scroggs 1988). This attitude can be either "good" or "bad". Choosing for an oral environment for example is "wrong" and therefore the attitude that leads to such a decision must also be "wrong". It seems that the choice of such a moral qualification depends on the decision it correlates with primarily.

Attitude ⟸ Decision ⟸ Action

Hence, the nature of the decision determines which moral qualification is chosen. This entails a deontological ethical perspective. Strictly speaking, deontological ethics also derives the moral standing of a specific decision based on the moral characteristics of the decision itself. The actor who takes a decision that is considered unethical, becomes an unethical actor him or herself. The right or wrong of decisions are hence defined in a moral space in which not the merits of its outcome but rather the decision itself is paramount. Indeed the discourse by authors such as Lane focus on the decision itself. For the most part Lane steers clear of deliberating about the specific merits of decisions in terms of a child's best-interest but rather draws a landscape in which certain decisions are deontologically depicted as immoral acts in themselves. The DC-ID succeeds in much the same objective. Since deafness is a culturally relevant trait, any act that conflicts with it must a priori be considered immoral.

Yet this portrayal is rather fragile. After all one may, as we did, disagree with the moral space authors such as Lane move in. Perhaps to substantiate their view further or

anchor it more robustly, Deaf discourse focuses on the "character" of the people who decide if the motives to choose are questionable, so must be the resultant of the choices made Generally speaking concepts such as "trait", "character" and "attitude" clear the road for a negative discourse (Brandt 1970)

> There is the thesis that an act is morally blameworthy only if it would not have occurred but for some defective trait in the moral character of the agent, and that it is morally praiseworthy only if it would not have occurred but for some superior trait in moral character of the agent - a view that is a development of Aristotle's suggestion (Nicomachaean Ethics, Bk II) that a necessary condition of an act's being virtuous is that it 'be based on a fixed and permanent quality' in the agent's character (Brandt 1970, 23)

As we briefly discussed, some moral philosophers depart from the notion that "intuition" drives how people deal with the moral dilemmas that they encounter, most evidently in virtue-based theorists These intuitions can be both "right" and "wrong" (Hare 1988) Some seemingly do not hold the common man's intuitions highly indeed Gutmann states that the focus on "bad character" is an "expression of general distrust" (Gutmann 1996a) Taba for example, believes that what drives people in their daily lives is "blind emotional reactions, prejudices and taboos" (Taba 1962) From Taba's formulation we conclude that she does not value these processes highly in the sense that she does not seem to consider them as being rational or virtuous The structure of the attitude-trajectory itself rhetorically predisposes for a normative or virtue-based ethical frame (Pellegrino 1985, Beachamp 1989a, Swanton 2001) Both the attitude and coping trajectory appeal to such a line of reasoning

Attitude $\Longrightarrow$ Decision $\Longrightarrow$ Action

Yet at least in the case of attitude, this line of reasoning does not work outside the moral space that we described Indeed this has also been claimed in the context of virtue-ethics in general, as "virtue" is defined as the "disposition to act or a habit of acting in accordance with moral principles, obligations, or ideals" (Beauchamp 1989a, Gewirth 1985, Veatch 1985) As such Veatch argues that it is not as "innocent" as it claims (Veatch 1985) If attitude is perceived as dichotomous in nature, being either "accepting" or "rejecting", the final ascription depends strongly on how one defines the case of deafness in moral terms In terms of "acceptance" it can only be ascribed in the moral space defined by the "unconditional love" paradigm In terms of "tolerance" it can only be ascribed in the moral space of "Deaf culture" Thus if we disagree with the moral space itself, if we question if deafness ought to be perceived as an identity or cultural trait, ascription of the evaluative concept of an "intolerant attitude" becomes rather unworkable Instead some have argued that we should look beyond the moral space defined by specific deontological principles and look for more general character traits, such as sympathy, affection and compassion (Beauchamp 1989a, Veatch 1985) We feel

that from this perspective parents succeed rather well. Still we remark that the use of character-ethics to deduce the ethical or moral status of an act, as commonly done in deaf literature, is questionable even in its theoretical assumptions (Gutmann 1996a). While "both right action and right motive should be present in a virtuous action", an action can be "right without being virtuous" (Beauchamp 1989a). Indeed Veatch argues that "in certain medical contexts it is really not critical whether the actors are virtuous" (Veatch 1985). Gutmann's critique is head-on and very much relevant to our subject:

> Utilitarians rightly remind us that attacks on motive and character distract citizens from the substance of issues. In Bentham's relentless inventory of political fallacies, "imputation of bad motive" is branded one of the "weakest" forms of argument. The fallacy consists in inferring from the alleged bad motives of the person who proposes a policy that the policy is also bad. [...] Talk about motive and character in this way produces a political discourse that is accessible only to those who can see what is "hidden", what is "behind" policies, rather than what is in them. (Gutmann 1996a, 171)

An inventory of MedLine and PsychLit databases reveals that many authors have nonetheless written about parents "attitudes" or "coping strategies" but close to none about the "motives" or "reasons" behind parental decisions. The resultant of this is that the above-mentioned moral space is upheld. However, if we would expand our perspective to include motives and reasons, we would inevitably be confronted with the moral space in which these "reasons" move. After all "reason" presumes a discourse, an argumentative space in which we argue rather than being either "tolerant" or "intolerant". Hence, by erasing "reasons" from an explanatory model, one predestines the moral debate in a distinct direction. The explanation for this is provided by the difference in pragmatics between "reasons" on the one hand and "attitudes" and "personality" on the other. Beliefs are generally considered to be cognitive states, while "attitudes" and "personality" are less so. Thus, the implication of the reigning explanatory models is that the parental decision does not qualify as "cognitive" casu quo "rational" but is rather subliminal. Parents are hence believed to decide based on prejudice rather than rational and critical assessment of the dilemma's encountered. As such parental values and the deliberation process they go through have been a relatively underexposed concept in deaf studies.

Our empirical study breaks with this deontological or virtue-based tradition that has characterized much of the moral debate about deafness so far (Beauchamp 1989a). While we did not ignore the possibility of a role of "attitude" and "coping", we allowed parents to speak about their rationale in contemplating their child's future. What emerged was a pragmatic and highly child-centered, de-essentialized and "best-interest" oriented discourse that largely overlapped with the moral space of normal parenting. This best-interest oriented position is much like the interpretation advocated by Buchanan (Buchanan 1989). In this chapter we continued to deconstruct the DC-ID discourse and as such redirected the moral space away from the essentialist cultural debate and towards the concept of best-interest. We have attempted to depict and analyze the best-interest of

deaf children as broadly as possible so to avoid the pitfall of catering to the antagonism between liberal and communitarian ideologies: our vision on best-interest is not limited to liberal values such as autonomy but encompasses concern over communitarian values such as socio-emotional well-being as well (Buchanan 1989). We have shown that DC-ID itself can be redirected to deaf children's best-interest. Actually we suggested that it evolves around this really and that the cultural discourse was "borrowed" on strategic grounds. We have shown that the communitarian view on deaf children's best-interest has specific merits that we should take very seriously. Yet we have also exposed the pitfalls and shortcomings of such a view, most importantly the threat that it evolves into an encompassing or "total" ideology that is blind to its liabilities and limits (Plamenatz 1971). We have shown that the liberal perspective has considerable liabilities, but we feel that the since liberalism represents some vital socio-cultural values, since the uncertainties surrounding the liabilities of liberalism as well as the feebleness of the communitarian alternative suggest that we should not retreat into Deaf culturalism categorically. For the time being we feel that "mainstream" values are and should remain the basis for deaf people as much as it is for hearing people (Taylor 1995). For the time being, Deaf culture remains a potential alternative scenario that we should track closely while actively considering its claims and warnings. This does imply, we feel, a carefully monitored and highly individual perspective on the well-being of deaf children. The package of individual deaf children will therefore always be an ongoing balance between our dominant moral discourse and Deaf culture discourse (Gutmann 1996a). This also implies that, at least initially, both avenues should be provided in, because the deaf child - once grown up - may choose both avenues. Depending on the individual context, of which parents are also a part, some children will be pitched more towards Deaf culture while others will become culturalized in hearing society mostly. Indeed most parents also seek such a compromise and as such seem to recognize the interrelatedness between the values depicted by either radical ideology. Deaf schools should abandon the way in which parents are "manipulated" and rather involve themselves in deliberation with parents. Deaf schools should abandon their generic quest for an "optimal solution", since by current standards it is unlikely to be found. Deaf schools should, more actively than they have done so far, really approach deaf children based on their individual capacities and embrace dominant philosophy instead of a priori retreating to a care-ideology, while also safeguarding the values represented by communitarianism. Serious attention to spoken language skills should be available and offered to all children who could benefit. All in all, the resultant of our efforts is that we have redefined the moral space of the deaf educational debate, away from the foundational Deaf culture argument and away from "character ethics" or virtue-based "attitude" theory to a rather eclectic beneficence-based form of utilitarianism or pragmatism that evolves around the concept of best-interest (Beauchamp 1989a). Eclecticism is to denote that our view on best-interest includes both liberal as well as communitarian values, both the need to safeguard "opportunity interests" as well as "human relationship interests" (Buchanan 1989): as such we recognize the values encapsulated in both liberal as well as communitarian discourses and depart from the "optimizing" aim that is rather characteristic for those preoccupied

with utility. Though we have shortly addressed parents from a virtue-based perspective, we underscore that there is a distinction between "right action" and "proper motive": "an action can be right without being virtuous" (Beauchamp 1989a). Indeed as we argued in chapter two, our narrative approach has described the landscape and shown us what the issues are. Next we need to make an inventory of the issues and analyse them orderly and sensitively. We will do so extensively in the next and final chapter.

CHAPTER 8 – ETHICAL ANALYSIS OF THE UTILITY OF COCHLEAR IMPLANTS

INTRODUCTION

Notwithstanding the approval by leading health authorities such as the American National Institutes of Health, the pediatric cochlear implant procedure has provoked strong and persistent objections from the Deaf community. The debate between implant teams and the Deaf community is ongoing and typically fierce in character (Balkany 1993a/1995/1996; Cohen 1994b/1995a,b; Davis 1997; House 1986; Hyde 1995; Lane 1997b; Lane 1997c; McCaughey 1995; Miner 1996; Pollard 1993; Rose 1994/1996; Shea 1993; Wever 1998). Implant teams are accused of negating the Deaf community, its rights, its values and its emancipation battles. British Deaf spokesman Ladd went even so far to draw parallels between cochlear implantation and the holocaust, by characterizing the technique as "Oralism's Final Solution", sadly enough triggered by rather bold utterances from some in the implant community (Solomon 1994; Alden 2001; Loeb 1993; Clay 1997). Though the response of most implant teams has been less truculent, some representatives have publicly and bluntly argued that *all* deaf children should be implanted and that the resultant disintegration of the Deaf community should be perceived as a virtue rather than a tragedy - of course much to the dismay of the Deaf community and quite a few hearing sympathizers as well.

> The simple fact is that if [American Deaf culture-ccw] could be reliably wiped out, it would be a good thing to wipe out. (Clay 1997)

As we have argued in the previous chapter, a principal argument of opponents of cochlear implantation has been rather "foundational", which implied a rejection of even the "perfect" implant. We have argued that such a position is contestable. In the hypothetical case of a "perfect" implant, the parental choice for such an implant seems at least as the most "reasonable" one in terms of a child's best-interest, since it would provide a sublime occasion to improve a deaf child's access to basic opportunities, while it would not result in the kind of moral liabilities that we discussed in the context of racial minorities. Yet implants are *not* perfect, so much is certain, and this is a crucial aspect to consider. Hence, while our discussion on the hypothetical case of a "perfect" implant was rather crucial to define our moral space, the conclusions that we reached do not simply apply to the case of cochlear implant technology as-it-is by current standards: the fact that implants are not perfect likely draws the case of "implants versus Deaf culture" much closer together. While the "perfect" implant is undeniably supreme in its ability to improve a deaf child's opportunities as compared to the route of Deaf culture, this is much less true in the case of actual implant technology – making it a much less "reasonable" choice that can "monopolize" our moral discourse. We must thus proceed with a contextual analysis of cochlear implants, that is based on the real-life potential and shortcomings of the technology as well as the real-life potential and shortcomings of Deaf culture to establish a deaf child's interests.

The controversy over pediatric cochlear implantation is ongoing and expands beyond the foundational Deaf culture discourse that we discussed in the previous chapter. If one aims to find "common ground" in discussing cochlear implantation, one needs at least an understanding of the nature of the disagreement. It is perhaps a logical start to shed some light on what philosophy and ethics have had to say on possible sources of disagreement in general - this without going into to much detail as this is one of the most extensive topics in contemporary moral and political philosophy. As Gutmann argues: "the temptation is to answer this question [moral disagreement-ccw] by turning moral disagreement into a simpler and seemingly more fundamental kind of conflict" (Gutmann 1996a). The most illustrative of this is perhaps when "incompatible values" are assumed to be at stake and a state of "deliberative disagreement" is reached (Gutmann 1996a). We should add that there is one aspect that is particularly tricky to the claim of incompatible values. Without ignoring the real possibility of incompatible values, we note that quite commonly agencies have resorted to the relative safe haven that it grants. Hence, we should be scrupulous here and not to accept such claims all too swiftly.

In the context of deafness, the issue of incompatible values came to the forefront most visibly in the DC-ID argument and in the conflict between "radical" liberalism and "radical" communitarianism as discussed in the previous chapter. As Gutmann states: "For communitarians, moral disagreement is simply a reflection of the fact that different communities have different fundamental values" (Gutmann 1996a). Deliberation can be of benefit here since it can "clarify the nature of a moral conflict, helping to distinguish among the moral, the amoral, and the immoral, and between compatible and incompatible values" (Gutmann 1996a). As such "citizens might discover that a conflict is the result of misunderstanding or lack of information" (Gutmann 1996a). Particularly in heated debates in which dialogue is not optimally facilitated, a situation may arise where both parties *assume* some rigid moral values in the other party -- a situation that may further harm rather than stimulate dialogue. Under the most extreme circumstances a situation may come into existence in which both parties retreat into the theorem of incompatible moral values, often convicting the other position as morally reprehensible. This in turn may lead to a situation in which both parties defend their positions in *extremes* - to add contrast to the conflict by standing behind moral values in their most primitive and unpolished appearance. When dialogue is finally opened and both parties show a genuine willingness to take a diagnosing look at the disagreement and the assumed moral values, it may well prove that the disagreement was in part the resultant of a lack of understanding rather than truly conflicting values.

A second issue that should be raised in this context is the possible impact of local circumstances. It may be that opponents are unaware of the assumed locality on which specific values are applied. If local circumstances differ, different values may prevail. Though this pragmatic axiom was certainly encountered in our interview material, our material also showed that pragmatism does not equate to relativism in this context since the range of potential values was limited. We argued that parents as well as Deaf culture

advocates such as Lane, reason in terms of best-interest primarily and that both draw on a rather similar value set. What separates parents from Deaf culture advocates seems to be how the values involved are "fitted" to reality. Parents and Deaf advocates differed in their views on "reality", which yielded a different ordering of values and ultimately a different outlook on desirable futures.

We have tried to disengage the threat of fundamental disagreement by employing deliberation about the assumed realities that both parties hold. We concluded that both have merits, both have some empirical correlate, yet neither has sufficient credits to assume an encompassing status that renders further deliberation default. We concluded that the "reality" that parents referred to was highly empirical and child-centered while the reality that deaf schools referred to was more aimed at the theoretical and political level, though reference was made to the empirical "reality" of deaf adults and concern over socio-emotional well-being rather widespread. We also concluded that parents incorporated the ambiguity between "challenge" and "indulgence" in their approach as they were continuously re-evaluating the fitness of their values to the "reality" that they encountered. Parents also seemed rather sensitive to the possibility that they might be wrong. Deaf schools were much less inclined to do so, indeed were much more inclined to uphold an encompassing reality to impose over all children. Deaf schools and Deaf culture advocates also were much less open to the possibility of being mistaken and were generally more dogmatic about their views. We suggested that the pitfall of such an encompassing narrative is that deaf children will be *categorically* excluded, while the realization of the advantages that Deaf culturalism (in its purest form) seeks, remain rather uncertain given the low-challenging environment at deaf schools and the dependency of these advantages on, for now unrealized, socio-political change. We argued that even if the utopia that Deaf culture advocates assume would materialize, serious moral questions such as the implications for the parent-child relationship, and liabilities such as the creation of "cultural commuters" remain. As such we argued that, while Deaf culturalism presents us with a valuable utopia, its basis is too weak and its liabilities too significant to allow it to override a liberal perspective on deaf children. As such we argued that aiming to facilitate a deaf child's potential to engage in hearing society by explicitly appealing to his or her spoken language skills while safeguarding his or her socio-emotional well-being and facilitating access to Deaf society is the most sensible course, though the exact execution demands a highly individually-tailored program. We feel that this eclectic and pragmatic course provides an opportunity to avoid the deadlock of deliberative disagreement. Still deliberation and disagreement will likely continue to occur at the local level, implying that evaluations of potential, resilience and potential sub-optimal functioning may differ.

It may also be that disagreement is not founded in conflicting moral values or different appraisals of the context in which values are to be applied, yet is primarily driven by a clash in self-interest. Since there hardly exists an objective moral reference frame with reference to income, negotiations on salary are perhaps the most illustrative

of this possibility, though this thesis is rather wide-spread in public policy in general (Gutmann 1996a) In particular in combination with the first possibility, this places us deep into contemporary moral philosophy The current debate on the social revolution of the 1960s, for example, swings back and forth between these two explanations In the Netherlands a public debate has erupted on the question what historical value we should assign to the events that took place in the 1960s and early 1970s Some explain these events in terms of moral theory, stating that the conflict was primarily driven by the fundamentally different moral values that young people held Others have framed the conflict in terms of a clash in self-interest, in which moral values were instrumental in legitimizing the conflict We note that some contemporary philosophers have promoted this latter standpoint to the level of theoretical postulate by claiming that ethics is ultimately rooted in self-interest or in local circumstances, that there is no essence, no fundamental values which we can use to navigate by -- hence spawning much skeptic haze on conventional ethics which assumes a difference between what is self-serving and impersonal values (Hart Ely 1981, Marcuse 1964, Foucault 1982) Some discourse theorists still hold that all disagreement is essentially a political struggle over autonomy and self-determination, which can only be solved through conflict, which makes plain bargaining the most suitable strategy (Habermas 1993) Others on the other hand persist that there *are* some values, such as liberty and opportunity, that transcend individual interest and that - although ethicists should include self-interest and the locality of values in their reasoning - ethicists should also incorporate those values that we share in our moral discourses and that they - while not falling victim to paternalism - should also dare to look beyond what people do or would like to do in practice (Gutmann 1996a) As such Gutmann argues that

> When individuals and groups bargain and negotiate, they may learn how better to get what they want But unless they also deliberate with one and another, they are not likely to learn that they should not try to get what they want When they deliberate, they move beyond conventional patterns of group politics that characterize the standard conceptions of interest group bargaining (Gutmann 1996a, 43)

In the case of deafness, this possibility seems appropriate in terms of the potentially divergent interests between the adult Deaf population and young generations of deaf individuals If both of these party's are recognized as "stake holders", one may aim to synthesize a view that caters to both fairly The problem with bargaining is that it is predestined to lead to a "political truce" rather than a synthesized and shared understanding, so to say The latter is more likely to be reached by the kind of "deliberation" advocated by Gutmann rather than union-like bargaining (Gutmann 1996a) Furthermore, bargaining does not seem to critically question the moral merits of the stakes itself that individual stakeholders are promoting (Gutmann 1996a, Benhabib 1994) As such it seems most fit to contexts in which no reasonable perspective exists to decide on such outcomes, which explains why bargaining is encountered most frequently in (income-) politics Yet we questioned these premises Though we argued that the narratives by deaf adults are crucial to our understanding of the moral and empirical

issues at hand, we questioned the legitimacy of granting them the status of "stakeholders" at the bargaining table to decide for deaf children, both on pragmatic as well as moral ground. Finally, bargaining seems to ignore potential power differences between stakeholders. It is for this reason that Alden has criticized the more compromising tone expressed by the US National Association for the Deaf (NAD) on pediatric cochlear implants (Alden 2001). As such Gutmann advocates a deliberative democracy that does not seek "consensus for its own sake but rather a morally justified consensus" (Gutmann 1996a).

In chapter seven we attempted to provide material to enlighten the moral issues involved in deaf education and to make the debate more translucent than it has been to date. As it showed, this did not result in a "simpler" sketch but we do feel that it provides a good basis to continue our deliberative process. We have argued that, essentially, the disagreement in the deaf educational debate does not so much center on incompatible values or "conflicting reasonable belief" as suggested by DC-ID, but rather on a different appraisal of a shared yet heterogeneous set of values that all pivot around the ambiguity of a deaf child's best-interest (Gutmann 1996a). Some deaf schools appeared to try to "settle" this ambiguity by retreating to an encompassing DC-ID discourse. Yet we have illustrated that the liabilities and uncertainties of this discourse, to which its advocates seem rather blind, makes it rather questionable. Rather we suggested that while we should uphold liberal values as a guide, no "uniquely correct solution" is likely to be found, given the variability and ambiguity of the local context (Gutmann 1996a). As such we argued for continuous deliberation on a context-sensitive basis and with consideration of both liberal as well as communitarian values, since they both represent valuable discourses in contemporary society.

In this chapter we will attempt to realize a similar goal in the specific context of cochlear implantation. We will scrutinize the cochlear implant issue by analyzing the premises of proponent and opponents alike. We will attempt to unravel the disagreement by analyzing the structure of the debate between implant teams and those opposed to the routine practices of cochlear implantation. In doing so we will depart from the assumption that the perceived legitimacy of every medical technique can be schematically represented by and consequently discussed in terms of a "benefit model". This is in concordance with our view on cochlear implants, which we stated in chapter six and seven to be aimed primarily at a child's best-interest. At least if we ignore the foundational cultural argument, we argued that opponents or skeptics of cochlear implantation must also depart from a similar position: they too are concerned over deaf children's best-interest and hence must also assume a "benefit-model". While we implicitly shed light on the benefit models of oralism and manualism, we have not *explicitly* scrutinized the benefit models operated by advocates and opponents of cochlear implantation. Buchanan and Brock have described the search for best-interest as follows:

> Thus the best-interest principle instructs us to determine the net benefit for the patient of each option, assigning different weights to the options to reflect the relative importance of the various interests they further or thwart, then subtracting costs or "disbenefits" from the benefits of each option. The course of action to be followed, then, is the one with the greatest net benefit to the patient. The mere act that a treatment would benefit the patient is not sufficient to show that it would be in the individual's best-interest, since other options may have greater net benefits, or the costs of the option to the patient - in suffering and disability - may exceed the benefit. (Buchanan 1989, 123)

Disagreement is unlikely to be directed against the device as such, but rather against its implementation, against its goals within a wider context. So, if we are to find the source of the disagreement we should look with some more detail at the debate on "benefit". We need to know how all parties involved morally frame cochlear implants before we can say if there is a fundamental incompatibility of moral values, misunderstanding or perhaps a conflict in self-interest. We will first have to explore to some more detail which values are exactly involved in the debate. We would argue that these values are not readily available in the arguments for and against cochlear implants, not even in the many rhetorical accounts that were published in otolaryngological journals some years back. Though our ultimate aim is to facilitate the deliberative process, it is uncertain if this will be achieved as Gutmann warns:

> Once the moral sensibilities of citizens and officials are engaged, they may be less willing to compromise than before. More issues come to be seen by more citizens as matters of principle, creating occasions for high-minded statements, unyielding stands, and no-holds-barred opposition. (Gutmann 1996a, 44)

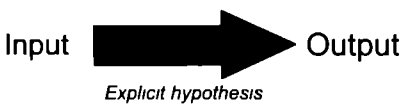
We recognize this danger yet we also agree with Gutmann that "moral sensitivity may sometimes make necessary political compromises more difficult, but its absence also makes unjustifiable compromises more common" (Gutmann 1996a).

Finally, a word of caution. The material presented in the previous chapters has the potential side effect of inducing a sense of indignation in the reader. Though we share this indignation to some degree, we would advice readers to keep an "open mind" nonetheless when proceeding with this chapter since this indignation has little bearing on the ethical or moral dimensions of cochlear implants. The fact that parents are lured away from cochlear implants based on questionable arguments and methods does by no means lead to a justification of the procedure, however attractive such a conclusion may be.

THE CLASSIC MEDICAL PARADIGM

To evaluate treatment efficacy consensus on outcome parameters needs to be established. Hence, in order to assess the merit of a medical technique such as cochlear implantation one will have to make use of a well-defined benefit model (Ten Have 1990).

Elementary benefit model



A benefit model should minimally contain one or more well-defined measurable effect parameters or "output" parameters that can be scrutinized in terms of efficacy. Furthermore, such a model should provide an explicit hypothesis describing the character of the assumed relation between the modifying parameter and what is being modified. Preferably, this hypothesis should allow the deduction of sub-parameters that in turn can be introduced into the assessment procedure as a check on causality. Furthermore, one will have to make explicit what risks and costs are involved.

For cochlear implants the input would be the implant, the causal hypothesis being the bypassing of a malfunctioning cochlea to a functional auditory nerve and intact central auditory pathways. Based on published cochlear implant trials, the output would most likely be measured in terms of functional audiological gain (dB). Risks have been quantified mostly in terms of "procedure-risks" casu quo medical complications.

Elementary benefit model CI

The most elementary as well as non-controversial of cochlear implant critiques is critique at the level of "construct validity", which deals with an inquiry into efficacy – though this definition has been rather simplified for our purposes. We label this criticism "elementary" to underscore that it functions within the same quantitative-theoretical ramifications and moral space as the conventional medical-audiological discourse on pediatric cochlear implantation. Criticism of this kind does not contest the suitability and

caliber of the defined parameters, rather it contests the internal statistical analysis on the given data set of, let's say, pre- and post-implant audiograms.

Ten Have mentions several issues that need to be addressed at this level in evaluating medical treatments: 1) efficacy, 2) risks and 3) costs (Ten Have 1990). Preferably medical treatments should have a high success rate and low risks and costs. In general increases in either risks or costs imply higher demand on the success rate and vice verse. This implies that there is no single fixed demand on medical efficacy (Callahan 1994). As such a relatively low-chance procedure *can* in principle be accepted based on 1) negligible risks and 2) low costs. So what have critics said about pediatric cochlear implantation from this perspective?

Even though this position is uncommon and not generally accepted to be sound, some have contested that there is a significant statistical correlation between pre- and post-implant data sets (Lane 1995; Lane 1997; Rose 1994). Significance in this context refers to probabilities on the Gaussian curve. A frequent and fully legitimate point of critique in this context has been the typical small samples studied, incomplete reporting (selection bias) and the lack of trend-reliability analysis when trends were introduced into the study format (Lane 1995). Given the small size of many studies, relatively large differences are required to be reliable at the 0.5 level. Lane also depicts the use of the "statistical mean" to report on cochlear implant success as he argues that an "outlying individual can have a disproportionate influence over the mean" (Lane 1995). He illustrates that if the median is considered instead, results drop.

Lane and others have also righteously claimed that though a correlation may exist, it is premature to conclude that the correlation is significant. Significance in this context alludes to the methodological concept of causality (Lane 1995; Lane 1997; Rose 1994). It has for example been argued that many other factors may co-explain why implanted children show improved audiograms: the age of onset of deafness, the intensive oral revalidation program and the high motivational level of parents being three main potential confounders. Lane criticized the study by Staller and colleagues based on the composition of the post-implant study group (selection bias), that consisted of far to many children (45%) who became deaf after the age of two (Lane 1995; Staller 1991b). If the mean is used to express success, the problem of a population strongly skewed by the inclusion of many children that become deaf after the age of 2 becomes even more critical since these latter children will likely perform rather well. Some plead for a case-controlled study, enrolling both implantees as well as non-implanted controls - both selected through the same stringent selection procedure - in a rigorous oral revalidation program (Lane 1995). Yet we add that even such a design would be inadequate, since it would fail to establish the necessary level of blinding. Parents of implanted children could very well prove to be much more motivated to engage in the oral stimulation of their child than parents of non implanted controls. The same could be true for educators, speech therapists and others in the child's ecology.

Lane argues that - given the above and given the large inter-individual variability of outcomes - current implant samples are so selective that hardly any *general* conclusion can be drawn from the given data, certainly not vis-à-vis the population deafened under the age of two that the procedure is likely to target. Critics fear that inclusion of cochlear implants into a regular health care provision will lead to an expansion of indications, which would lead us to unknown territory given the above. Such a practice of gradually moving-indications and the resultant expansion of potential recipients has been described in the context of renal dialysis for example (Rettig 1984; Kolata 1984). After renal dialysis was qualified as a Medicare treatment in 1972, the number of recipients increased fourfold within a single year and tenfold within a decade. As Kolata illustrates, this explosive growth was at least in part the result of changing indication criteria as "the new dialysis population includes patients with serious chronic illness such as cancer and heart disease and senile patients who are delivered to dialysis centers three times a week from their nursing homes" while its case was originally advocated based on otherwise healthy young patients with end-stage renal disease (such as hemophilia) (Kolata 1984). Indeed there are indications that a similar trend is taking place in the context of cochlear implantation (Balkany 2001). We feel that Lane's comments have some potentially serious implications on cochlear implantation. Most importantly, his critique should alert us on the state of implanted children who became deaf under the age of two, since his argument suggests that the efficacy of cochlear implantation in this group has not been proven as convincingly as one would desire. To deduce the benefit of this group from the gains reported in the group of children who became deaf after the age of two is a perilous act. Lane's suggestion that this latter group is likely to outperform those who became deaf before the age of two seems to be supported by our findings in chapter six. Though we said that we could not exclude the role of revalidation-time as a confounder, parents of children who became deaf after the age of two reported significant better outcome and were significantly more satisfied with the results. While the abundance of information on implant results in children who became deaf after the age of two may be explained by the desire of implant teams to produce positive results, we should be careful to carelessly translate these findings to the much larger group of children that become deaf before that age.

CRITIQUE ON THE CLASSIC MEDICAL PARADIGM

Introduction

Typically, a medical empirical research hypothesis, and in particular its output parameters, is rather one-dimensional in its form: selected parameters are limited in number and have a quantitative biomedical character. In the previous section we referred to this confined workspace as the "classical medical paradigm". Notwithstanding the fact that it is frequently encountered in medical literature, the above-mentioned paradigm is not without problems (Musschenga 1987). As a matter of fact, social scientists have addressed these problems abundantly over the past 4 decades or so. Addressing the inadequacy of the classic medical paradigm can be qualified as critique at the level of content validity. Indeed critics have claimed that the main problem of modern medicine lies not in its inadequate statistical skills but rather in the assumptions that are made prior to any such analysis and that shape their paradigm. One "content validity" issue is of particular importance in this context: the dissimilarity between "output" or effect as measured by medicine and "benefit". Output and benefit are thus not considered to *necessarily* overlap but are considered to be distinct concepts in this context. At the end of the justification chain of each and every medical procedure one will have to make a leap in which measurable output or effect is linked to what is believed to be of general human benefit (Reinders 2000; Musschenga 1987). Each and every one-dimensional output parameter must be related to a wealthier and closer-to-life concept of benefit. In this section we will review the general debate that has surged in medical philosophy and ethics surrounding the issue of benefit vis-à-vis medical treatments and the critique on the classic medical paradigm that it entails. In the next section we will apply this critique in the context of cochlear implantation.

The "technological imperative"

One of the main critiques on modern medicine has been that it has assumed effect and benefit to be more or less synonymous. The so-called technological imperative critique is central in this context. This critique consists of several layers, most of which can be made relevant to the cochlear implant debate. One layer is of specific suitability and will be discussed in more detail. This layer consists of the "self-evidence" or "self-justification" that medical procedures have claimed since the successes of the 16^{th}-19^{th} century, which is related to the symbolic "sense of unlimited opportunity", "unbounded hope" and "the politics of progress" that has surrounded healthcare well into the 1960s and continues to be of influence even today (Ten Have 1998; Callahan 1994; Verbrugh 1972; Oderwald 1985). Skeptics are not welcomed in this atmosphere as Verbrugh points out.

> 'Scientifically researched' is the hallmark for reliability of thus reached knowledge and insights, providing the legitimacy to apply this knowledge in real life and casts clouds over those in opposition to this practical implementation. (Verbrugh 1972, 127 – translation ccw)

The social-existential need for resolution of suffering combined with an unabridged cultural belief that medicine *can* achieve this has led to an equation of medical intervention to "the good life" and as such induced a context of almost unlimited self-expansion of medical technology (Wever 1996; Buchanan 1989).

> The idea that the good life is something objective, something supra-individual, is best illustrated in medicine. The good life was after all a healthy life. (Musschenga 1987, 112 – translation ccw)

It may be this belief that explains why broader perspectives or quality-of-life parameters are typically not included in evaluating new medical technologies, but rather only after controversy rises over the merits of these technologies in meeting their heroic life-saving claims as the case of coronary bypass surgery illustrates (Musschenga 1987). If medical intervention is a priori considered to be synonymous to the good life, we need no supplementary perspective to measure medical treatments. As argued, this perspective on medical treatments has been criticized. Few medical interventions can guarantee that the abyss is circumvented and the correspondence between what medicine *can* achieve and the profundity of human suffering is at best partial (Oderwald 1985).

> Humans have many levels of functioning: the physiological level, the physical level of everyday activities, the level of psychological stability and health, the level of social functioning in the direct social environment (such as the family) and in society (such as in employment) and the level of the all encompassing experience and valuing of existence. Interventions at one - physiological - level has impact on other levels. There is a statistical-correlative between the original intervention and the final effects on physical, psychological and social functioning, but no deterministic-causal relation. (Musschenga 1987, 98 - translation ccw)

Indeed, Smith feels that patients hold a "bogus view" on the abilities of medical science (Smith 2001). Yet it may be so that physicians themselves have also internalized this "omnipotent" perspective to some extent, which may make it difficult for them to accept that quite a few medical treatments are not as "heroic" or "self-evident" as thought (Smith 2001; Jensen 1987; Blume 1997).

On the other hand it may seem rather unlikely that physicians are unaware or ignorant of the rocky relation between medical treatments and the good life. Yet this awareness seems more in the reign of construct-validity so to say: medical treatments may fail and may produce sub-optimal results, yet the *potentiality* to yield the good-life often remains beyond doubt. One could argue that as such the uncertainty of medical

treatments only adds to the heroic demeanor of the medical profession After all, if success were guaranteed and effortless, the physician would be more like a car-mechanic than an archetypical hero Heroes derive their status from their selflessness fight against something evil that is often supernatural and more powerful than themselves (Pearson 1989) As such, medical treatment is framed as a battle against nature, against fate, against the odds The next citation from Time magazine illustrates the relevance of this metaphor to the medical profession

> Patients think of him as a guardian angel Nurses call him a god Virtually every week for the past three decades, pioneering transplant surgeon John Najarian--an Olympian figure with the physique of a linebacker and the self-confidence to match--has ventured into the operating room at the University of Minnesota Hospital to battle death And more often than not, he has won Patients he has saved can vividly recall the surge of hope they felt when Najarian gave them his simple vow "I can do it " (Nash 1995)

In a classic mythical sense, the metaphorical virtue of the effort lies in the threat of defeat one can better die fighting than in surrender Hence the essence of the physician as modern-day-hero is that he or she battles the evil *in spite* of the odds However as the above readily illustrates, the "heroic battle" of medicine is often depicted in the scenario of life and death Hence, at least in the domain of life-saving procedures, medicine may be inclined to consider its efforts unambiguous and self-justifying Indeed, Ten Have and colleagues speak of a "no lose philosophy" which reigns in medicine, a philosophy that departs from the basic notion that it is considered worse not to treat and face *certain* defeat than to make a treatment effort and run into failure (Ten Have 1998)

Hence the origin of the technological imperative seems to be the case of life-saving medical procedures This can be readily understood since without this form of health care "people will not be able to exist" making it a "first-order necessity" (Loewy 1990) The certainty of a lost life if treatment is not offered is considered *so* weighty that it is inclined to a priori legitimize virtually any treatment attempt (Tijmstra 1987) Or as Buchanan and Brock verbalize it "If one thinks of this judgment as resting on a comparison of the harms and benefits of existence with the harms and benefits of nonexistence, one is liable to succumb to a metaphysical anxiety attack" (Buchanan 1989) This may be depicted as the rhetorical nature of life-saving procedures that fits the heroic metaphor rather well

Critique at the self-justifying rhetoric of life-saving procedures

In spite of what we have stated above, critics *have* aimed their arrows at medicine's no lose philosophy in the domain of life saving procedures As a matter of fact the critique against the technological imperative actually originated in this medical domain Triggered by advances in life-sustaining medical technology in 1950s and 1960s authors

such as Van Den Berg and Illich critically examined the wider consequences of medicine and as such questioned its underlying paradigm (van den Berg 1969, Illich 1975) These technological developments stretched and clouded the area between life and death, which weakened the self-justifying case of being "potentially" life saving As an extreme example, mechanical ventilation allowed medicine to save lives, sometimes even indefinitely in the case of the persistent vegetative state, yet evoked thorny questions regarding the value that we should assign to such a life In terms of Loewy's statement on life being a first-order necessity, we can ask the critical question what do we mean exactly with "life" or "existing"? Does biological "existing" satisfy our demands (Musschenga 1987)?

Hence *even* in the case of first-order treatments activism is not by definition the only logical choice, at least if we include a wider and more detailed benefit perspective, which critics have claimed we should If we do not adopt such a perspective and if we do not actively include the concept of benefit into our appraisal of medical treatments, the physiological "effect" of a treatment is separated from the existential "benefit" to the patient Indeed "the purpose of all treatments is ultimately to benefit patients, not just create an effect" (Schneiderman 1990, Churchill 1994, Buchanan 1989) Paraphrasing Callahan

> Too often the only test of a new technology is whether it brings immediate relief to a medical problem But what are its likely long-term medical consequences? If it is a therapy that will cure a disease or save a life, what will be the state of the life that has been saved and the societal implications of saving such lives? We need also now to ask of a proposed technology what it will mean for the overall life of the patient, not simply the immediate good of the body (Callahan 1994, 169)

Again a comparison with the mythical hero may be illustrative In most instances, the battle of the mythical hero is depicted as an individual battle really though the fight is self-sacrificing at the same time, implying that the benefit of a possible victory lies with others than the hero him or herself The suggestion is that the hero and he alone will carry the burden of a lost battle, in the worse case he will die If the hero succumbs, society may have to continue to suffer from the victorious evil, yet this was doomed to be the case before the hero made his attempt to overturn the situation This depiction is not fully applicable to the case in medicine however While the physician-surgeon may physically fight the evil of disease, this evil takes place *inside* the physical body of someone else While the physician may grieve over a lost battle, the one who holds the highest stakes is the patient him or herself The patient, both in terms of treatment process and outcome, hence explicitly must experience the battle An analogy would be that of the mythical hero who chooses to battle an evil emperor, yet the latter retaliates by cutting down on food supplies rigorously, hence causing suffering in the wider population as the consequence of the battle process itself In terms of outcome, a lost battle may prompt the emperor to strike back against his people, hence potentially making the result of the lost battle *worse* than the situation before Indeed, one could

argue that this scenario is much more real to life. In either case it does represent the reality in which physicians battle disease much more accurately. In medicine this implies that both the process as well as the detailed outcome should be considered when evaluating medical treatments, even if they are potentially life-saving. The fight against disease may itself incur serious suffering for those who are ill and the disease may strike back in terms of outcome as well. Loewy defines two views in this respect.

> In the vitalist presumption, life itself (at least human life) is a 'good' worth pursuing at all costs. Those who cling to this point of view see the value of life as self-justifying: life (at least human life) is of value because it lives. [...] Those who do not share such a point of view consider life to be of value as the necessary condition for experience or, put in a different way, to be of value because of the biography that such a life underwrites. Such a point of view will focus on the nature of the experience rather than merely on the biological condition of life itself. Viewing life as the necessary condition for experience and sustaining life for that reason implies a healthy respect for social conditions. (Loewy 1990)

Therefore what Loewy addresses is that we should not fall victim too easily to the previously mentioned heroic "no-lose" connotations of the technological imperative and as such should actively scrutinize life-saving procedures. In this scrutiny, outcome measures should not be restricted to biomedical effect parameters such as physiological life and death. Such outcome definitions are simply inadequate as the case of comatose patients illustrates (Musschenga 1987). This awareness has led to an increased scrutiny of medical technology. Many medical successes are not without liabilities, at least if the one-sided medical, "physiological" or "organ" perspective is disposed of (Verbrugh 1972; Churchill 1994).

> We are dealing with treatments that, even if they fully succeed, never lead to a re-establishment of health. The odds of complete success are less - sometimes considerably less - than 100%. These treatments sometimes bear high risks of serious side effects. (Musschenga 1987 – translation ccw)

Notwithstanding the natural appeal of life-saving procedures, an extensive debate has indeed been raised regarding so called "medical futility" (Miles 1994). What if we succeed in saving lives, yet the quality of some of these lives proves to be rather limited or hindered by treatment complications (Musschenga 1987)? What if we succeed in saving lives, but the length of that life is limited by the nature of the underlying disease in question or the advanced age of the patient, thereby limiting the time during which "benefit" can be enjoyed (Taffett 1988)? Yet potential process liabilities - read side-effects or burden of treatment- should explicitly be accounted for as well. What if we can save lives yet have to submit patients to extremely rigorous treatment protocols? What if in saving a single life, we have to subject many others to long and intensive treatments unsuccessfully in terms of survival? What if saving a single life induces massive costs to our collective health care system, therefore potentially limiting resources to other patients

in need? Hence critics have prompted medicine to look not only at effect or outcome ("battle won or lost") but also at the broader context of the battle itself as well as its detailed contextual outcome. Focus on the outcome of the metaphorical battle alone would ignore the reality of the patient who is the subject of the battle and hence has to endure it as well as live with its consequences.

Formulating success in a "physiologic" way, such as functional audiological gain in cochlear implantation, "embryo transfers" in the case of IVF or "cardiopulmonary recovery" in the case of CPR, may drive up the success rate yet this is mostly of scientific-medical value rather than social or ethical value per se (Ten Have 1995; Hilhorst 2001). The value of medical treatments may not be restricted to but should always include the non-medical context in which people live their lives (Jacobs 1991). As Mol states: "it is not enough to know if something works, which in itself is hard enough, but also how it works out, what the effect is on the daily lives of those involved" (Hilhorst 2001). This is particularly true if the goal of medical intervention is quality-of-life rather than restoration of a bodily function. This notion is in concordance with Callahan's principle on "health symmetry":

> The principle of symmetry is this: A technology should be judged by its likelihood of enhancing a good balance between the extension and saving of life and the quality of life. Its aim is to promote medical coherence, by which I mean outcomes that foster the rounded well being of persons, not simply one-dimensional improvements that benefit some aspect of individual well-being at the expense of others. No technology can guarantee a rounded outcome in this sense, but if well developed it can promise a high probability of such results. A healthcare system that develops and institutionalizes a life-saving technology that has the common result of leaving people chronically ill or with poor quality of life ignores the principle of symmetry. (Callahan 1995, 165)

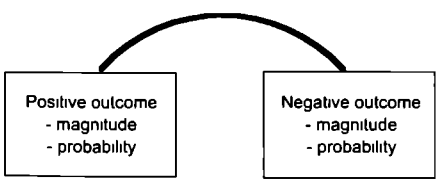
As Musschenga has eloquently illustrated in the context of quality-of-life research however, stating such a demand is easier than translating it into a usable and morally unambiguous format (Musschenga 1987). Defining quality-of-life is a rather blurry task. Should we aim for example at "minimal" standards, "optimal" or "normal" standards of "ideal manhood" or perhaps "self-reported satisfaction" (Musschenga 1987)? Musschenga suggests that the definition should co-depend on the context in which it is operated. This seems related to the merits of the alternative of non-treatment that we will discuss in the next paragraph. If the alternative of non-treatment yields a serious compromise on quality of life, reducing it below minimal standards so to say, it makes little sense to insist on "optimal" standards for the treatment option. Furthermore, quantity of life cannot be discarded from the appraisal, the two seem interrelated to some degree. This in turn makes it rather complicated to decide on balance. How do we deal with a procedure that yields a great benefit to quantity of life while quality is rather low? And how do we deal with the reverse, with treatments that yield only little benefits in terms of the length of life yet contribute much to that life's quality?

The proportionality principle

Hence critics have prompted medicine to look beyond physiological effect and move towards the real-life details of process and outcome in the context of patients' lives. The rise of quality-of-life studies is an exemplar of this (Musschenga 1987). While we believe that the goal of such a new outlook on medical treatments should be awareness and scrutiny first and foremost and as such do not believe that the balancing problems that we discussed above can be overcome by some arithmetic formula, we do feel that some of the principles of quality-of-life research provide a good guideline. The concept of "proportionality" is such a useful principle.

Once we have reset our mind and have broadened our view beyond the rhetoric of a no lose philosophy, a rather rich tapestry of outcomes will confront us. Some treatments can have both positive and negative outcomes. Chemotherapeutical cancer treatment can result in a positive outcome in terms of extending life, yet this may happen at the cost of long and severe treatments. Yet the final outcome may in itself also yield both negative as well as positive results in the different domains of benefit. Cancer treatments may extend life yet result in permanent disability as well. As we argued, we somehow face the task to weight positive and negative outcomes when evaluating a medical treatment. Hence a next step in the process is that we evaluate the proportionality between the magnitude of positive benefits related to the magnitude of possible negative liabilities, which is a derivative of two major medical virtues: beneficence and nonmaleficence (Beauchamp 1989a). In light of the Hippocratic tradition, physicians need not only aim for optimal positive effect but minimize the liabilities of their treatments as well (Beauchamp 1989b).

Figure proportionality balance



To make a fair appraisal we will also need to know something about the likelihood that positive and negative outcomes occur. If the chance of extending life is very slim while the probability and magnitude of severe side effects is considerable, our judgment of a treatment will likely be different compared to cases with a very high likelihood of success. As such Buchanan and Brock suggest the following formula for establishing "utility" (Buchanan 1989):

Utility = (probability of benefit x magnitude of benefit) - (probability of harm x magnitude of harm)

As we said, one could proceed with Buchanan and Brock's formula by actually allocating "points" to each side of the equation. Yet the allocation of points to failure or success is very difficult if not impossible and bound to be rather subjective Callahan states that disciplines that do attempt to realize this, are "designed to provide us with clean answers to muddy questions" (Callahan 1994). In this respect, numbers wrongfully "bypass values" (Callahan 1994) Ultimately answers to such questions are political in nature since there is no neutral paradigm to determine which value system to apply (Callahan 1994) Having said this, we should protect ourselves against the threat of moral relativism that underlies this view. The fact that we cannot allocate precise numbers does not imply that we cannot deliberate about medical treatments conforming to the template depicted by Buchanan and Brock. Medical treatments should be subjected to some sort of risk-benefit analysis, however great the temptation to resort to the heroics of a case-based "no lose philosophy". Risk-benefit analysis presupposes openness to treatment results as well as possible liabilities, which will likely induce a more reasonable climate to discuss medical treatments (Musschenga 1987). It requires a shift from thinking in terms of biomedical effect to the concept of benefit. From the above it results that it will be equally unlikely that this will result in new sets of rules but rather a "general direction of thought and action providing a basic framework for making decisions" (Callahan 1994)

Outcome relative to non-intervention

If we depart from Buchanan's formula on utility in a concrete case it becomes evident that something is missing, namely context. In the case of chemo- or radio-therapeutical cancer treatments for example, the main positive outcome is likely to be physiological survival while negative outcomes may be issues such as illness, pain or nausea due to treatment, baldness, fatigue, depression and disability While the magnitude of benefit may be argued to be "significant" (for the sake of argument we set it at a perfect score of 1), the probability of it occurring is often rather small (for the sake of argument we set it at 40% or 0 4) The probability of harm to occur can be large indeed (for the sake of argument 80% or 0 8), while the magnitude can also be significant (for the sake of argument 0.2) If we would depart from Buchanan's concept of utility, this could lead to the conclusion that utility is positive yet rather low.

Utility = (0 4 x 1) - (0 8 x 0 2) = 0 24

Yet positive and negative outcomes cannot be viewed by themselves. The benefits of intervention are always relative to some norm, the norm of non-intervention forms the other side of the coin so to say As such it provides the proverbial landscape in which positive and negative results are weighted The legitimization of an intervention also lies in the relation between the positive and negatives at *each side* of the treatment coin,

which is also expressed by the standard of case-controlled studies (Musschenga 1987). Returning to Buchanan's formula this would result in the next formulation of "relative" utility (T stands for treatment, NT for non-treatment):

$$\text{Utility} = \frac{\text{T(probability of benefit x magnitude of benefit) - (probability of harm x magnitude of harm)}}{\text{NT(probability of benefit x magnitude of benefit) - (probability of harm x magnitude of harm)}}$$

If we expand our view to relative utility, it becomes clear that to assume benefit is rather inappropriate in non-treated oncology cases. Indeed to project a concept such as benefit on a deceased patient is questionable (Buchanan 1989, Musschenga 1987). Thus what remains on the non-treatment side of the equation is the probability of harm. Indeed it can be argued that the probability of harm is high (for the sake of argument 80% or 0.8) and that the magnitude of harm will also be considerable (for the sake of argument 0.2), though both do depend on individual factors as well as the success of palliative care. In the case that treatment is offered, as we argued, the probability of benefit expressed as survival may be moderate, yet the magnitude is rather large. In terms of harm, the probability as well as the magnitude is high, though oncology is continuously making an effort to minimize at least the process or treatment related harm through chemo-protective agents. As such it could be argued that the harm-sides of the equation "cancel" each other out in favor of the treatment option. Suffering due to treatment is hence down-played by the argument that suffering would *also* occur if no treatment were offered. Moreover the low chance of survival is put in perspective by arguing that death is rather certain if no treatment is offered. Indeed it appears that from this perspective the relative utility of cancer treatments materialize better than if we navigate on utility in itself. As a matter of fact, this is perhaps the logical-schematic representation of the no-lose philosophy that we discussed before.

$$\text{Utility} = \frac{(0.4 \times 1) - (0.8 \times 0.2)}{0 - (0.8 \times 0.2)}$$

Yet this assessment does not seem entirely fair: there are some problems with it. Firstly, we may criticize the attribution of a "perfect score" to the benefit of treatment. Secondly, it does not account for the differences between successfully treated patients and those that fail. Finally, it assumes that the treatment option should define the character of output measures in the non-treatment option.

Thus the assumption that if successful we should attribute a "perfect-score" to the magnitude of treatment benefit is questionable. In the above we reasoned that the benefit of a successful treatment is rather large in magnitude. Yet this latter assumption is at risk

of being restricted to the biomedical paradigm or, if it expands its perspective, being biased to the assumption that medical treatment reinstates life *as it was*. The former was argued to be undesirable as shown by the case of the persistent vegetative state. The latter is a highly optimistic perspective on medical treatments. Even certain "successes" in terms of effect may nonetheless be attributed a negative-score so to say. While this latter point may seem subjective in the context of oncology it is more evident in other life-saving procedures such as CPR. Outcomes are often sub-optimal and as such form the Achilles tendon of CPR. Most large studies report that around 15% of in-hospital resuscitations are successful in terms of survival to hospital discharge. At least 10% of these survivors suffer from neurological damage (van Walraven 2001). Additionally about 40% initially do survive the resuscitation yet pass away during the hospital stay (Ten Have 1995). Emergency medicine has been concerned over these numbers as evidenced by numerous retrospective analyses in medical literature. This has resulted in quite a few guidelines assisting the physician in his decision to initiate CPR or not and when to sustain CPR once commenced (van Walraven 2001; Thompson 1998). While in oncology "success" cases may suffer from treatment related morbidity, this is rarely as severe as it may be in resuscitated patients, for example in the case of persistent vegetative states as a sequel to CPR. The fact that many medical treatments do not reinstate normalcy implies that a thoughtless equation of treatment effect to a satisfactory and even self-explanatory benefit is fallacious. For many years this issue remained unidentified by the medical profession, as the result of a lack of awareness as well as the fact that detection often requires qualitative and long-term prospective trials (Callahan 1994). Slowly more and more evidence is accumulating however. Some cancer patients may survive after treatment, but for many this survival does not equate a return to normalcy (Matsuoka 2001; Velikova 2001; Brown 2001; Madalinska 2001). Measures of post-treatment quality-of-life are increasingly discussed in oncology research to decide on the most favorable treatment modality, sometimes even compromising level-of-treatment to some extent (Matsuoka 2001; Wallace 2001). Wallace for example describes several long-term liabilities in the case of pediatric cancer patients: 1) second primary tumors, 2) cardiovascular disease, 3) infertility, 4) educational, psycho-social and quality-of-life issues and 5) growth related issues (Wallace 2001). Preterm infants can perhaps be saved at 24 weeks of gestation, yet we now know that many suffer from morbidity as adolescents and young adults. Hence, medical successes are not "perfect" nor are they free from risks or liabilities. The likelihood and degree of harm is of importance and will vary depending on the treatment under scrutiny (Ten Have 1995). The harm instated by medical treatments may be physical as in the case of harsh courses of chemotherapy. Yet harm also includes less tangible psychosocial factors such as the liabilities of prolonged exposure to the medical regime, false hope and disappointment.

As we suggested, the representation depicted above limits our scope on the benefit that non-treatment may have to offer to the moral space defined by treatment. What we are doing in fact is balancing two different types of harm. The harm depicted in the numerator is related to the process of treatment mostly, while the harm depicted in the

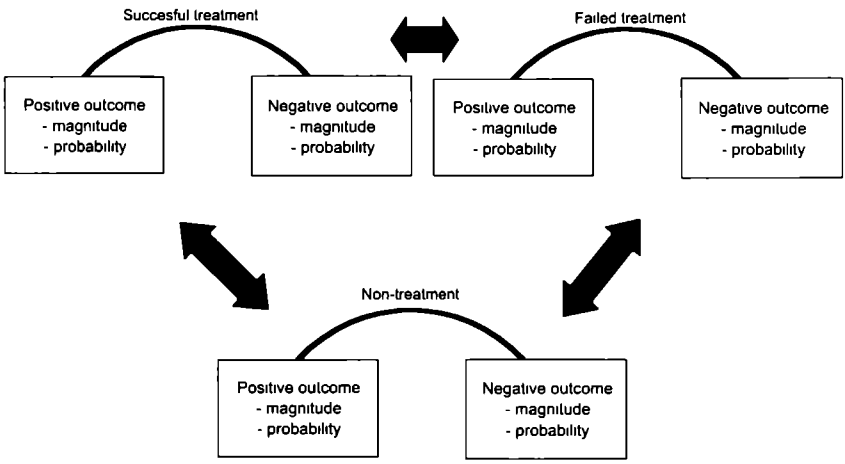
denominator is related to process of dying The latter has not been accounted for the case of treatment *failures* sufficiently That is to say, the depiction above may be argued to be fair, but it is fair in the case of *successfully* treated patients only People who are successfully treated will not experience harm due to the process of dying and as such the harm they *are* exposed to due to treatment may be suggested to be "temperated" by the harm due to the process of dying in untreated patients Yet if treatment fails, as it is rather likely to do in the case of quite a few life-saving treatments, this argument is inadequate This is to say that if treatment fails, patients will have to endure *both* the suffering due to the process of treatment as well as the suffering due to the process of dying Furthermore, these people will have to deal with a third form of harm that is the result of disappointment over treatment failure Positive outcome may in such a case be formulated in terms of the emotional comfort of having "at least tried" yet the magnitude of this benefit is debatable (Buchanan 1989) As such one could argue that the harm-sides of the equation do not neutral each other out Only the harm of the process of dying is balanced out, leaving treatment failures with the harm due to the process of treatment To make things worse, failures will not benefit from the promises of active treatment As such from the perspective of treatment-failures, the utility of treatment materializes as rather disappointing to say the least Yet we cannot predict who will succeed and who will not, so how are we to incorporate the divergent perspective of the successfully and unsuccessfully treated? It seems fair to at least add weight to the harm-side of the treatment protocol Buchanan utilizes the Baby Andrew case to illustrate this point and warns that we should not blindly discount the negative effects of treatments and treatment failures for the sake of a chance of survival (Buchanan 1989, Stinson 1981)

> The sad list of Andrew's afflictions, almost all of which were iatrogenic [treatment caused], reveals how disastrous this hospitalization was Andrew had a months-long, unresolved case of bronchopulmonary dysplasia, sometimes referred to as "respirator lung syndrome" He was "saved" by the respirator to endure countless episodes of bradycardia and cyanosis, countless suctionings and tube insertions and blood samplings and blood transfusions, "saved" to develop retrolental fibroplasias, numerous infections, demineralized and fractured bones, iatrogenic cleft palate, and finally, as his lungs became irreparably diseased, pulmonary artery hypertension and seizures of the brain He was, in effect, "saved" by the respirator to die five long, painful, and expensive months later of the respirator's side effects (Adapted from Stinson 1981)

Finally we may further narrow down what we said about the non-treatment option Is it fair to allow the treatment protocol to set the benchmark for outcome in the non-intervention alternative as we did? If we pervasively define "benefit" in terms of physiological survival, the benefit of non-treatment is negligible indeed Yet if we depart this axiom and look at what the non-treatment option offers in terms of benefit relative to the treatment option, different issues may come to the forefront, at least if we make a comparison with treatment failures One could argue that being able to live without medical care and treatments is such a benefit Vis-à-vis the harm side of the equation, we already referred to the role of palliative care If palliative care is well provided in and

timely organized, it could be argued that the dying-related magnitude of harm may be less as compared to the treatment option, at least if we assume that those in a treatment protocol are more likely to die in a "suit of armor" so to say.

Figure proportionality balance



Thus to access the utility of medical treatments we should broaden our view beyond medical effect towards the magnitude and probability of positive and negative outcomes that a treatment may result in for the patient. Evaluation of utility must be dependent on the relation or balance between these outcomes. Yet the case of treatment failures may not be adequately represented in such a view and results should be placed into the context of the non-treatment alternative. To avoid that the non-treatment alternative is immediately discarded because of its negation of the positive outcome that treatment seeks, it is beneficial to consider the latter beyond this restricted perspective. This is especially true if the likelihood and magnitude of positive results are scanty and its relevance becomes particularly clear in the case of treatment failures. To continue to frame the non-treatment option in the context of its inability to realize the positive results treatment seeks, underrates the value it may have in terms of benefit for patients and is inclined to reinforce the no-lose philosophy that we address here. However scanty, the non-treatment option does potentially have something to offer for patients in the context of treatments that have a very low likelihood of success and that induce very high liabilities on their way. As such it should preferably not be discarded a priori. It is this perspective that has likely triggered interest in the concept of informed-refusal in the context of medical oncology. It is also this perspective that has likely induced the advancement that palliative care has experienced over the last few decades. Granting the non-treatment option a fair place in our appraisal implies however that our formulation

becomes even more unfit for simple numerical analysis than we suggested previously, given the heterogeneous contributions made by the various alternatives. Rather than hoping that simple arithmetic formulae can solve the problems we face, we suggested that we must engage in dialogue with ourselves as well as the patient to appreciate the complexity of the situation and tentatively explore our options.

Who is to decide?

In the previous sections we have tried to present our view on benefit in the case of low-chance yet potentially life-saving procedures. We have shown that, if one abandons a unilateral biomedical perspective, the issue evolves into a rather rich tapestry. Though we used Buchanan's arithmetic model, we also emphasized that the weight attributed to each item in fact remains a subjective enterprise. Rather we used his model for its illustrative power and to structure our deliberations. Yet if the final weighting of the issues involved is in essence subjective, this places us for a considerable problem, namely the problem of how we are going to reach a final judgment in the case of low-probability though proven effective medical treatment? On the one hand our material suggests that ultimately only the patient him or herself can decide. After all we argued that one is unlikely to find an objective tool to gauge the benefits and liabilities that we depicted. Yet while this may be true vis-à-vis the concrete patient-physician setting, there are some significant problems with such an individual n = 1 perspective. We will try to shed more light on this potential discrepancy between the individual with a responsibility towards him or herself only, and the physician who carries responsibility towards all his patients.

Physicians can choose not to offer a medical treatment to a patient in spite of its proven ability to yield success. Recently for example, neonatologists at the Leiden University Hospital decided to refrain from offering treatment to premature infants born before a gestational age of 25 weeks, even though some of these children *can* actually be saved by intensive-care treatment (Tommiska 2001). While this has been common practice in most other neonatological intensive care units (NICU's) in The Netherlands and even though treatment of such children has been critically examined as far back as 1974, it is currently not common practice internationally (Musschenga 1987; Duff 1973). In spite of meager survival statistics and high morbidity many NICU's actually continue to offer treatment pretty much regardless of gestational age, sometimes treating newborns as young as 22 weeks. Yet the reason for this difference in protocol does not necessarily stem from a different appraisal of utility, but is rather explained by other factors. One important factor is the discrepancy between the patients' individual and physicians' overall perspective (Rebagliato 2000). Indeed Musschenga states that in the context of quality-of-life, a thorny question has become who is to decide on this, the autonomous patient or the physician who is trying to realize beneficence (Musschenga 1987). Seemingly the two need not coincide, particularly not in modern day autonomy-based ethics.

In an individual case, physicians may tell the following story to parents in terms of cost and benefit. On the benefit side, the child may have let's say a 40% chance to survive up to hospital discharge (Tommiska 2001). On the down side, the child consequently has a 60% chance to die in spite of having suffered from frequent complications, such as respiratory distress syndrome, sepsis, necrotizing entero-colitis and bowel perforation, and in spite of been subjected to lengthy and intensive treatments. Moreover, if the child survives, he or she has a significant chance (60-100% for children born < 25 weeks) of suffering from permanent disability such as neurological deficits, oxygen dependency and blindness (Tommiska 2001). Yet these statistical numbers do not really materialize in an n = 1 setting, at least not in the same way as they do in an overall perspective. These numbers say something about the chance of events that *may* occur, but they do not alter the "realities" with which parents can be confronted as the result of treatment. These "realities" may be argued to be rather twofold: treatment either succeeds or it does not, the child will either live or he will not. It is not difficult to understand that in such a scenario quite a few people will choose for treatment. The chance of disability may be a "risk" that parents choose to take and a risk with which they believe themselves to be able to deal with. For the parent of a preterm infant, the choice to forego with treatment is hence more likely to be considered as a non-choice really. Why would the parent of a preterm child option for non-treatment, even if the odds of survival are infinitely small? Wildavsky speaks of the "principle of perspective" in this context:

> Morbidity and mortality, in tabulating aggregate rates of disease and death, describe you and me but do not touch us. We do not think of ourselves as "rates". Our chances may be better or worse than the aggregate. To say that doctors are not wholly (or even largely) successful in alleviating certain symptoms is not to say that they don't help some people and that one of those people won't be me. (Wildavsky 1987).

The same is more or less true about the physician that accompanies parents and presents them the option. Physicians have been inclined to reason along similar lines: "will *this* patient benefit from this treatment?" is a common question (Callahan 1994; Wildavsky 1987). The inconclusiveness that such an answer is likely to provoke, implies that some patients will be withheld treatment while they *could* have been saved, thereby confronting physicians with a moral dilemma. Stories about miracle cures likely fuel this dilemma (Arts 1985). As Truog states:

> Even in theory, statistical inferences about what might happen to groups of patients do not permit accurate predictions of what will happen to the next such patient. In addition, the tendency to remember cases that are unusual or bizarre predisposes physicians to make decisions on the basis of their experiences with "miraculous" cures or unexpected tragedies. (Truog 1994)

For the physician too, the decision may be perceived primarily as a twofold one, one of victory or defeat. Again, the numbers add little to such a view. The concrete patient-physician relationship may play a role in this process as well. As we said, patients likely

reason from a local, individual or private setting and as such may choose to accept liabilities on a personal account. Simplified, a treatment either works or it does not and patients may "accept" the chance of failure in their individual context A patient or his surrogates may simply choose for or even demand a relatively low-chance procedure with a relatively high burden of treatment (Truog 1994). Assuming what we have stated above and assuming that consensus is reached that a specific treatment has a low chance of success, the situation may arise that an individual patient decides differently in terms of treatment desirability, thereby placing the physician before a considerable dilemma: given the context in which medicine is practiced, physicians are likely to feel a predominant responsibility towards their individual patient's desires. It poses the physician for a considerable problem from an ethical point of view, since what is potentially at stake here is patient autonomy to participate in decision-making (Miles 1994; Bellah 1985; Truog 1994). As such Miles states that there is a tension between a physician's judgment of "medical futility" and patient autonomy in marginally effective treatments As Reinders states, emphasis on the patients right to decide "reflects a deep-seated democratic impulse, namely the tendency to believe not only that people are entitled to make decisions regarding their own lives, but also that only they know what is best for them and that they will behave responsibly in making these decisions" (Reinders 2000). Churchill states that, though the old paradigm that upholds patient autonomy is valuable, it also yields new problems. One of these problems is that the right to demand is derived from the more fundamental right to refuse

> The right to refuse is basic and essential to autonomy, this is the sovereignty of which Mill spoke The right to be left alone is fundamental The right to receive is something different (Churchill 1994)

Indeed "it will take wise physicians to protect patient autonomy without lapsing into paternalism" (Churchill 1994) As Truog states· "The decision that certain goals are not worth pursuing is best seen as involving a conflict of values rather than a question of futility" (Truog 1994) We agree with Miles however that "those who claim that autonomy should always override determinations of medical futility seem to have an elitist view of 'autonomy' that only makes sense if one assumes the existence of a privileged class of health care consumers" (Miles 1994). The environment in which decisions are made by patients may not always guarantee calculated decisions. Yet physicians are said to be poor judges of patients' preferences and their authenticity (Denis 1988). This is not to say that physicians should be empowered to refuse marginally effective treatments if the patient or family requests this, even though jurisprudence has been carefully in favor of this. But awareness of this context should instigate physicians to at least carefully describe the decision a patient is about to take, hence to at least provide adequate information required to make a sensible decision. As Mol has correctly stated, this information needs to be translated beyond statistics for patients to realize and empathize with the nature of the decision (Hilhorst 2001) Furthermore it seems insensitive to steer clear of any scrutiny of patients' motives all together, based on the

belief that conflicting values must be at stake and the risk of "giving options disguised as data" and ultimately of paternalism (Younger 1988). Incomplete or incorrect information, profuse agony or unrealistic fear may just as well influence the decision-making process and physicians should make an effort to clarify and resolve this (Truog 1994; Brennan 1988; Churchill 1994). Still, to discern "rational" from "irrational" motives remains a fundamental and likely pertinent source of bias and paternalism (Churchill 1994). Threats of litigation may also play a role. Notwithstanding the numerous clinical guidelines that have appeared on CPR, Marco and colleagues have found for example that many physicians ignore these reports, in part because of fear of litigation (Marco 1997). Hence, the clinical decision to forego with resuscitation is based on juridical grounds or "convenience" rather than evidence (Franklin 1994). Yet there is another reason to question if we should perceive of the physicians' pledge to beneficence as primarily located in the patient-physician relationship, as an endlessly repeating chain of case-based judgment as depicted above. The roots for this tension are embedded in the Hippocratic oath, which contains both dedication to the patient as well as the "art" of the medical profession, and may hence be said to be rather fundamental to medicine (Toulmin 1989). When we depart from a global perspective, statistics do not so much teach us what the risk of an event is in an individual case, but rather gives us a clew of the magnitude of the effect that we instill with our treatment. If a 24-week-old immature baby stands a 10% chance of survival, from a global perspective this implies that we will have to expose 90 similarly real cases to intensive care treatment to allow 10 to live, while perhaps half of those that do survive suffer from disability. It seems rather logical that from this latter perspective, the fate of failures becomes rather significant. In times of scarcity this relevance may be verbalized in economic terms (Commissie Keuzen in de Zorg 1991). Yet it is relevant from an ethical perspective as well.

Conclusions

The classical medical paradigm is inclined to equate physiological effect to benefit. In this section we have shown that this habit stems from the context of life-saving procedures. Since physiologic life is at stake in such treatments and physiological life is the absolute prerequisite of existential life, medical intervention has been depicted as imperative. We called this the rhetoric of life-saving procedures, which forms the basis of the technological imperative or "no-lose philosophy" that influences our thinking about such treatments significantly. Yet social scientists have criticized this most heroic domain of medicine nonetheless. The origin of the critique is set in the 1960s when technological advances clouded the distinction between life and death and as such clouded the self-justifying rhetoric of physiological life. The most extreme example of this is the persistent vegetative state. These developments induced a call to expand our perspective on benefit and utility beyond physiologic life and stressed the need to make a fair inventory of positive and negative results of medical treatments, even if life is at stake. As such we need to establish not only the magnitude of positive and negative

results, but need to be informed about the probability that they occur as well. Finally we must form a judgment on the proportionality between positive and negative outcomes. In doing so, the context of the specific treatment is of relevance. Thus we should form our judgments in light of the merits of the non-treatment alternative. Finally we argued that we must not restrict ourselves to the analysis of individual cases, but should form an opinion based on a supra-individual level as well. In the case of low-chance treatments, this may more fairly bring the lot of treatment failures to the forefront. Indeed if we look at medicine today, it appears that many disciplines have taken this critique at heart. Extensive quality-of-life research is proof of this in spite of our previous critical notes. Perhaps more so than other disciplines, medical oncology acknowledges the potential liabilities of their treatments and actively seeks to improve this situation. Its treatments are often rather low-chance and induce significant liabilities. Medical oncology seems to have acknowledged that a no-lose philosophy is inappropriate in this context. Great care is taken to reduce the liabilities of treatments, through chemo-protectives and fractioned doses of radiotherapy for example. The treatment-failure side is also actively included in the strategy and certainly not ignored. Many modern oncology departments offer more than cure alone. They offer counseling and support, in the case of treatment failures as well. Moreover, many departments have gained expertise in the field of palliative care, which is an integral part of what these departments have to offer. In the next section we will apply the broader view on utility that we have drawn onto the case of pediatric cochlear implantation.

EFFECT AND BENEFIT IN THE COCHLEAR IMPLANT DEBATE

Introduction

In spite of what we have discussed in the previous section, most medical treatments have little to do with life and death Nonetheless, the imperative to treat or at least the notion that people have "nothing to lose" when opting for a treatment sometimes seems to influence decision making in these fields as well Hence, while the origin of a no-lose philosophy may be life-saving treatments, its derivatives such as the bravado "I can do it" attitude, bias towards intervention, focus on the "potentiality" of success and neglect of the fate of failures has been adopted to other domains of medical intervention as well (Ten Have 1987) Extensive and broad scrutiny of the positive and negative effects of a treatment relative to non-treatment is rarely performed, which leaves the bias towards treatment untouched Some treatments may be highly effective and produce very few liabilities, which makes the latter not so much of a problem Yet if effectiveness is moderate or low and liabilities rather real, the principles of what we have discussed in the previous section seem much more relevant Given what we have discussed in the previous chapters it seems that there are indeed potentially distinct liabilities in the case of pediatric cochlear implantation Moreover, if we expand our view of benefit beyond the decibel, the probability of "success" cannot be qualified as self-justifying As such scrutiny of the procedure is desirable

The suggestion that medical interventions silently assume, and ought to assume, a correlation with broader levels of functioning, is even more compelling in the case of cochlear implantation (Ten Have 1998) The classical medical paradigm, with its focus on cure, is "deficient" in the case of chronic states such as deafness (Ten Have 1998) We cannot "cure" deafness and as such we cannot retreat to the self-justification rhetoric linked to cures that we encountered in the case of life-saving procedures We can *improve* hearing through cochlear implantation, yet we need to show if and how this improvement materializes into *benefit* to a deaf child Nonetheless it is mostly decibels we are measuring so far Even though some maintain that this is a satisfactory model of benefit and assume that any increase in sound awareness is sufficient to legitimize cochlear implantation, such claims are typically not founded by argument or evidence and stand risk of catering to the prejudice "agony of silence" that we discussed in chapter three

We previously discussed "efficacy" in the context of the classical benefit model of cochlear implantation As Musschenga proceeds

> To establish the effectiveness of a service, we first must establish what the relevant benefits and liabilities are, then measure their size to finally measure their relative weight and make up the balance (Musschenga 1987, 139 – translation ccw)

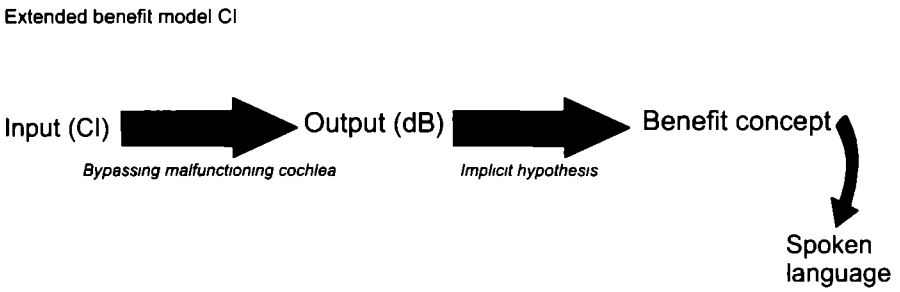
In discussing the classical benefit model we hence skipped a crucial step since we failed to thoroughly discuss the relevant benefits and liabilities. It is precisely this point that many critics are addressing. In the case of the cochlear implant debate many critics have attested that instead of quarrelling about internal methodological significance regarding p-values and causality, we should be talking about significance from a broader perspective by challenging the implicit core of the classical medical benefit-model, its implicit promises so to say. Hence, though it is audiological output that we measure, there ultimately must be some wider implicit or explicit conceptualization of benefit or the good life that legitimizes the technique. A first step in the process should hence be to verbalize this more detailed benefit model. Given our discussion in chapter seven, where we defined best-interest as the moral space of our analysis, it seems most appropriate to use this concept in this specific case as well, though we will use the concepts of benefit and best-interest interchangeably. How do we perceive cochlear implantation to cater to a child's best-interest? As we argued in the previous section, evaluation of utility is also dependent on the negative outcomes that it may produce. What negative outcomes in terms of a child's best-interest should we incorporate in our analysis? In addition to defining positive outcomes and identifying negative outcomes, we should also make an estimate of their magnitude and likelihood to occur if we want to be able to make a balanced judgment. We have also maintained that positive and negative outcomes must be related to the context of non-treatment. Hence, once we have defined positive and negative outcomes we should look into how these factors fare in the case of non-treatment. This requires a scrutiny of the Deaf culture alternative. Since we have scrutinized the Deaf culture non-treatment alternative extensively in chapter seven, we will only refer to it instrumentally in this section. Finally we advocated that we expand our perspective beyond the individual case in analyzing this medical procedure.

The benefit model of cochlear implantation revisited

As we stated above, implant teams may insist that they actually aim to restore a physiological function, namely the function of the cochlea, and that as such proof of restoration (or "prosthesizing" or "replacing") of cochlear function is an adequate measure of treatment efficacy. Yet as we have stated, even though such logic has validity, it is of scientific value mostly and does as such not automatically lead to a treatment imperative. The restoration of a damaged bodily function is by no means an obligation, barring perhaps the most extreme "professionally-deformed" individuals. Rather, bodily functions are restored *because* people are assumed to be restricted by their dysfunction, because restoration of these functions is assumed to be of benefit to patients. In the case of CPR, the function of the cardiopulmonary system is restored because it is a prerequisite for biological life and biological life is a prerequisite of any existential "good life", though we also showed that it can also be the prerequisite of a not-so-good existential life. Yet as we argued, this rhetoric is not simply applicable in the case of cochlear implantation. The distance between restoration of the cochlear function and "the

good life" is far greater than in the context of life-saving treatments. Moreover we argued that cochlear implantation does not "restore" the function of the cochlea, but can at best *improve* it. This only adds to the distance between cochlea-related outcome measures and what we are after in this context: a child's best-interest. Still we feel that it would be shortsighted to perceive of audiology as a profession that has fallen victim to professional deformation, as a profession that has foolishly equated the decibel to benefit. Rather, the decibel materializes as an objectively measurable *intermediary* between the cochlear implant and benefit or the good life. If this is indeed the case, there must be an implicit hypothesis that links audiometric gain to benefit.

The addition of simple language tasks to most cochlear implant assessment projects may be perceived as a hint of the structure of the cochlear implant benefit-model. Implant teams do not implant to attain a net audiological improvement; rather they do so because such an improvement is considered a causal prerequisite for acquiring oral communicative skills. From this perspective it appears that the oral language premise is of great importance indeed.

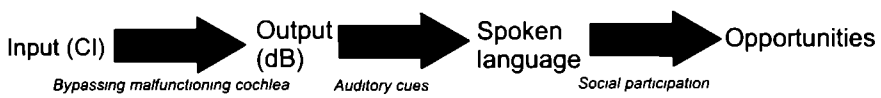


Does the legitimization chain of implant teams halt at spoken language? Do they feel that spoken language in *itself* justifies the procedure? Or does giving value to spoken language represent yet other values? Given the subdued information that implant teams provided parents, one may suggest that sound awareness and spoken language skills are indeed the objectives of implant teams. Yet, as we said previously, we do not see exactly how this necessarily adds much to a deaf child's best-interest. Up to the 1960s those in favor of spoken language may have upheld this latter assumption nonetheless. After all, before the groundbreaking work of Stokoe Sign language was not considered a full language, which may have strengthened the idea that language could best be realized through the dominant spoken modality. Yet Stokoe's work has clearly dismantled this assumption, even though some feel that Sign language has less degrees of freedom compared to spoken language (Stokoe 1960; Menzel 1998). Hence in itself, thus depleted from the context that some implant teams seemingly want to avoid, not hearing seems

only a "minor problem" in the context of the difficulties that a deaf child faces and as such it seems rather odd to suggest that hearing in itself justifies surgery.

Indeed we suggested that context is rather crucial here and as such we should make our views on benefit more explicit. Spoken language is potentially of benefit because it is perceived as a valuable asset in realizing a child's future opportunity interests. This view is fully supported by parents' perspective on cochlear implantation as we described in chapter six. It is also much more congruent with the sense of "essentialness" that surrounds cochlear implants, in the way it has been depicted in the public media and the way it has evolved in the debate between proponents and opponents. As such we would argue that the central claim of cochlear implantation is or ought to be that it facilitates spoken language acquisition to a population with very limited capacities to realize this without the implant and that in turn spoken language is valuable because it is assumed to expand deaf peoples future opportunity benefits. Schematically this would look as follows:

Concluding benefit model CI



If we look at the critique at cochlear implants based on this benefit model, roughly two responses can be identified. On the one hand those that more or less agree with the content of the definition of benefit and hence move within the same moral space, yet disagree with the validity of the construct of the benefit model. This critique was discussed previously and we will add to it in this section. On the other hand we find those who disagree with the definition of "benefit" or "best-interest" itself and hence disagree with the validity of the *content* of the benefit model (Preisler 1997; Fletcher 1995). As we outlined in chapter seven, the most extreme example of this latter critique is encapsulated in Deaf culturalism. Though we will not discuss this ideological alternative at length, we will incorporate the values that are represented by it vis-à-vis the best-interest perspective as well as the critique that we formulated opposed to it. As we argued, these values include both liberal or guardian issues related to "opportunity" and an "open-future" as well as communitarian or gardening issues such as "human relation interests" (Buchanan 1989).

Construct validity critique

We discussed Lane's legitimate construct validity critique previously vis-à-vis the most elementary benefit model of cochlear implantation. Yet his critique, as well as the critique expressed by many other linguists, also affects the benefit model represented above. Hence Lane does not only question if the results as published by implant teams are significant and causal, he *also* questions the suitability of the instruments used to actually measure "benefit" as depicted in this benefit model (Lane 1995). The core question now becomes rather technical since it evolves around the question what exactly constitutes "spoken language". If one claims to measure "spoken language" as outcome, one's instrument must be designed for and fit to actually measure this. Clearly Lane feels that the instruments used by implant teams reveal that their operationalization of "spoken language" is rather rudimentary and deficient. More concretely he rejects the relative lack of open-set speech recognition as a measure of outcome. We add however that, as we discussed in chapter one, since Lane's reply several studies have analyzed outcome in terms of open-set speech recognition (Tyler 1997; O'Donoghue 1998; Summerfield 1995; Snik 1997a/b). Regarding the studies that did include open-set speech recognition, Lane criticizes the fact that when visual cues were allowed, hence when children were studied in an environment where they could actually see the speaker, no comparison was made with the situation without the implant. Commenting on Osberger's study (Osberger 1991):

> The children averaged 7.6 years of age and had received extensive aural/oral habilitation; they would be expected to have learned to lipread a certain number of high frequency words, some of which may have appeared on the common phrases test. (Lane 1995)

Moreover he condemns the methodology of these studies much in the same way as we discussed in terms of the elementary benefit model. Finally he warns for "experimenter bias" as the result of the lack of blinding: investigators may unconsciously "score" an implanted child favorably.

Content validity critique: liabilities vis-à-vis the non-treatment alternative

It is clear that cochlear implantation critics consider oral language skills alone unsatisfactory in considering a deaf child's best-interest and as such dismiss the benefit model that we presented. This is not to say that they contest that oral language skills should be included in a benefit-model, rather they feel that in contemplating a deaf child's best-interest we should look at the issue from a broader perspective. Critics feel that a deaf child's best-interest is not *determined* by his or her future speech ability alone, a position that is underscored by Buchanan's view on best-interest. If we depart from such a broader view, we also have to establish to what degree cochlear implants actually contributes to and to what extent it possibly harms a child's best-interest. As such the

critique on cochlear implants is largely congruent to the critique on oralism and educational mainstreaming that we discussed in chapters four and five. Cochlear implants thus seem to be perceived as a potential cradle for increasing spoken language demands and mainstreaming efforts. One could argue that what critics mainly berate is how liberal values threaten to override a deaf child's current as well as foreseen future socio-emotional needs (Buchanan 1989).

The foreseen threats to current socio-emotional needs is based on the assumption that parents who choose for cochlear implantation do so to circumvent Sign language or to trade Sign language for oral-aural communication rather swiftly. As we explained in chapter four, deaf ecology strongly opposes such action. It was argued that a young deaf child's best-interest should predominantly be perceived in gardening terms, in terms of his or her socio-emotional needs (Markschark 1997). Sign language is believed to be superior in this respect. It allows rapid language acquisition and as such provides a rapid means to establish meaningful relationships. As a low-threshold and low-stigma language, it allows deaf children a "normal" childhood rather than being confronted with their inabilities and having to work hard to *achieve* in spoken language. The most reasonable place for these issues to be realized is deaf school, which has the added benefit of allowing young deaf children smooth, symmetric interaction and more meaningful interaction with peers. Yet our study has shown that this fear does not materialize in the case of cochlear implantations. Most of our cases energetically engaged in Sign language course and some of them continued to use Sign language in the home environment for many years after implantation.

The foreseen threats to future socio-emotional needs were also omnipresent. There are at least two argumentations that explain this. Firstly, the psychodynamic arguments of early childhood injury. Second, the argument referring to the future need of "human relation interests" in which mainstream society is considered unattainable. Regarding the first, all of the issues that we discussed in the previous paragraph were considered paramount for healthy socio-emotional functioning in the future, as the case of orally trained deaf adults is believed to prove. Indeed, critics find strong support for this belief in biography of the adult deaf (Laborit 1994). Additionally, a large body of psycho-emotional research has scientifically scrutinized this issue as we discussed in chapter one: many studies have reported significant psycho-emotional problems, up to 50% higher than in the normal population (Hindley 1997). Even though we do not contest these numbers and feel they are highly significant, there are some problems with the argumentation. Although the evidence of increased psycho-emotional stress in general deaf populations is beyond any doubt, we feel that a lack in well-being is too informally explained in terms of language choice. Other risk factors can clearly be identified in this population, institutionalization and additional handicaps being prime candidates (Yarrow 1963). Hence, evidence of a *causal* relationship between spoken language and psychological injury is not conclusive. The narratives of deaf adults cannot replace this omission. Given the central role of self-reported linkage between suffering and oralism,

we recall that memory is not always the most reliable source of information about actual circumstances, particularly not if these are affect-laden (Perry 1975; Rubin 1996; Conway 1996). Comprehensive early life-stories such as those by Deaf author Laborit may well represent what Kris has labeled "personal myth", be it an inverse version so to say since Kris linked this subject to the suppression of traumatic experience (Kris 1975; Conway 1996). Regarding the second, skeptics do not believe that the results of cochlear implantation will be sufficient to allow mainstream society as a reasonable platform for "human relation interests". This issue hence refers to the feasibility of cochlear implantation to succeed, both in terms of magnitude and probability, which is by all means an issue we should take very seriously. Our empirical study suggests that critics may be correct in their assumptions. Given the experiences of orally "successful" deaf adults, it seems appropriate to assume that many implanted children will experience difficulty from both a social as well as societal perspective. Indeed it has been anecdotally reported that even highly educated deaf individuals with reasonable oral skills experience great difficulty to actually engage in society (Van Noort 1999). Still one should account for the fact that little is known about those deaf individuals that do succeed in mainstream society, since their lot has hardly been studied and these people are said to be rather inconspicuous (Bertling 1994). The assumption that all deaf people fail in the mainstream combined with the fact that science and politics have exhibited a lack of interest in those who succeed has been a major incentive for some oral deaf people to claim a political voice in The Netherlands. Nonetheless we feel that these arguments make interaction with deaf peers a potentially valuable asset.

Yet as we discussed in chapter seven there are some potential dangers to this argument. While we acknowledged the values of communitarianism and as such feel that deliberation about human relation interests are exceedingly important in providing an adequate and balanced view on deaf children's future best-interest, we have also shown that it stands at the root of the encompassing DC-ID narrative, in which "specialness" and "vulnerability" are coercively assigned to deaf people based on the assumption that alternatives "cannot be done" and all that rests us is to make sure that deaf people lead "comfortable" and sheltered lives (Markshark 1997; Ogden 1979). This in turn potentially paves the road for what we considered to be excessively segregating and unilaterally care-oriented policies (Schwartz 1997). Moreover, if we focus on psychosocial well-being alone, our benefit model stands the risk of ending in an encompassing argument in which "happiness" or "belonging" become the alpha and omega of best-interest so to say (Beauchamp 1989b; Dawes 1994). In chapter seven we criticized such an extreme position, since it ignores liberal values and ignores the interdependence between psycho-emotional well-being and liberal values as autonomy (Csikszentmihalyi 1999; Swierstra 1998; Musschenga 1987). Furthermore, we argued that such a perspective is inclined to aim for "optimal" solutions, which are likely to create distinct liabilities on their way (Achterhuis 1980). This may come as counter-intuitive for some social scientists since, as Wallach has argued, many psychologists assume that rewards for the (effective) self are the ultimate ethical principle (Wallach

1983; Vitz 1994). The most visible manifestation of this is perhaps the exponential growth of interest by social scientists in the concept of "self-esteem", particular in American society (Vitz 1994). Some critics have declared this development as symptomatic of profound narcism, others perceive of it as a sign of social bankruptcy where the failure to meaningfully involve all social groups into our society is accepted as a given, which in turn results in providing those excluded with an environment in which they can at least "feel good" (Dawes 1994). We should further consider that (immediate) psycho-emotional well-being as an absolute measure of benefit may function as a trap, since it will in itself only be satisfied with a full signing environment. Oral language acquisition is after all by definition a more demanding goal for deaf children as compared to Sign language. Hence if the underlying premise is that such demands should be avoided as much as possible in the case of deaf children, a Sign language route will always prevail. Hence, if the value of spoken language is subordinated to (immediate) psycho-emotional well-being, a consensus seems rather far away.

Yet there appears to be another level of critique, which can be encountered in linguistics and which does not refer to the threat that liberal values come to override a deaf child's current and future socio-emotional needs, but rather contests the liberal values to which cochlear implants are believed to cater through facilitating spoken language skills. This argument thus challenges cochlear implantation on its own turf of "future opportunity interests" so to say (Buchanan 1989). Though linguistic arguments may be perceived as a "counter balance" of achievement and performance in terms of oralism - emphasizing the need to unload the "formal learning machine" in oral training and to facilitate socio-emotional needs - they may on the other hand be perceived as quite the opposite. This version of cochlear implant critique is essentially synchronous with the radical communitarian course of Deaf culturalism that we discussed in chapter seven (Spivak 1990). Brunerian-Vygotskian language theories demonstrate a rather strong preference for what is labeled the "higher-cognitive spectrum" of language development (Meadows 1996). Rather than focusing on static language aspects such as lexicon and syntax, language is viewed as the medium through which a child dynamically shapes him or herself in the context of their relationship to others and their membership to culture (Meadows 1996). It seems rather self-evident, at least theoretically, that such ideals will thrive "optimally" when fully submerged in Sign language and Deaf culture. At least theoretically Sign language would provide the best opportunity in terms of autonomy and an open-future, as it is a language without barrier in which a deaf child can develop him or herself optimally. As we explained in chapter one, the evidence for this thesis has been gathered from Deaf-Deaf studies: many studies have demonstrated that deaf-hearing adolescents lag years behind their hearing peers in terms of cognitive development while an equal number has shown that Deaf children from Deaf parents do considerably better. Still, we suggested that the methodology of these studies leaves some questions unanswered. The incidence of additional handicaps is, for example, higher in deaf-hearing children. Moreover, many of these studies have been institution-based, thus potentially missing successfully mainstreamed children of hearing parents. Geers feels

that the low-challenging environment of many deaf institutions is to blame (Geers 1989). While Deaf-Deaf students can compensate for their "deficient" education in the home environment, deaf-hearing children cannot. Finally Gallaway and Wol have suggested that the different language development of deaf-hearing children as compared to those of Deaf parents, may not necessarily be synonymous with worse: rather deaf-hearing may follow a different route to language (Gallaway 1994). While we would not dare to contest the facts presented by these studies, these latter comments may suggest that the difference between Deaf-Deaf and deaf-hearing children is smaller than proposed. In chapter seven we criticized the radical communitarian view from a different perspective. We argued that there is no conclusive evidence that their promises will indeed materialize into "benefit" on the long run, not even if the political premises of this view are realized. What "benefit" will a small or marginal edge in cognitive development entail if a deaf child has limited access to society, its educational institutions and its media? Of what "use" will the gain in cognition be if a child has no room to express it in, as Field's concept of literacy range illustrates (Field 1998). Indeed, some studies have suggested that orally schooled deaf individuals may actually do better in terms of societal functioning (McCartney 1987; Hollman-Borsjé 1990; Bonnema 1977). Sure, we can "force" society to open its doors to the deaf, but how likely is this to occur and how do we judge the social isolation that will be the result? Moreover, we argued that the instatement of such a reality would induce significant liabilities, both in terms of potentially separating a child from his or her biological family as well as the societal liability of convicting the Deaf community to a rather permanent isolation or making them into "cultural commuters". These liabilities do not rebut the critique but do suggest that we should abandon encompassing strategies and seek a balanced perspective when contemplating deaf children's best-interest.

Conclusions

We have shown that cochlear implant critics feel that to use oral language as the sole outcome parameter of a benefit model is rather inadequate. It is felt that by doing so other factors that constitute a child's best-interest are wrongfully ignored. Critics feel that this may result in a situation in which these additional factors will be systematically overlooked and even overrun, which should be perceived as a serious liability. It is feared that "current socio-emotional needs" are overlooked since it is assumed that parents will ignore Sign language when they choose for cochlear implantation. This ignorance is furthermore reasoned to damage a deaf child's future socio-emotional interests as well, as depletion of early childhood Sign language is conceived of as the cradle of adulthood psycho-emotional injury. Future socio-emotional interests are also feared to be compromised by the assumption that implants will ultimately fail to yield sufficient spoken language skills to actually engage in hearing society while the opportunity to socialize in Deaf culture have not been provided sufficiently. Finally cochlear implants are perceived to be at odds with a child's optimal future opportunity interests, though this

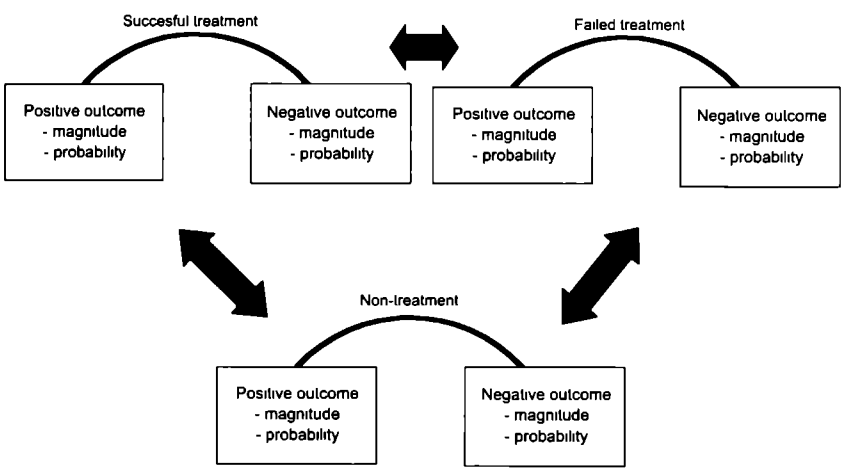
was based on the equalization of "opportunity" to language and cognition. Hence, the oral route is postulated to yield not much of either world: a deaf child will not reach the goal of social participation through oral routes and will lack adequate cognitive and language skills to engage in society through Sign in more formal modes. Though we have criticized some of these assumptions, we do consider their intention rather relevant in this context. The critique at the level of a deaf child's current socio-emotional needs may be read to say that there are *limits* in trying to involve a deaf child in mainstream society through teaching oral language, a position many of our parents underscored. Particularly the critique that appeals to the anticipated sub-optimal magnitude and low probability of the outcome of cochlear implantation are considered substantial. Indeed it may very well be that if implants do not yield enough spoken language skills, the assumed benefit in terms of a child's future opportunity benefits do not materialize while his or her future socio-emotional interests are actually compromised. We thus need to know how much spoken language proficiency we can expect from cochlear implantation. We need to ask ourselves to how much benefit this magnitude will translate. We need to establish probability of this occurring and analyze the fate of those that fail.

THE THREE PROPOSITIONS OF THE CI BENEFIT MODEL

Introduction

The heroism of a truly life saving procedure lies in the fact that it silently claims to reinstate biological life if successful, while biological life is most essential to any form or shape of existential life. Yet as we argued this is a rather misleading portrayal. Many cancer patients have to live with the chance of relapse and many suffer from morbidity as the result of the disease or its treatment. Moreover the probability of being successful is typically rather low, implying that many patients have to endure treatment without ever getting to enjoy the fruits of success. Yet this information is rarely conveyed to patients. Moreover, even if it were it seems unlikely that patients would actually "process" it, given the *absurd* situation they are facing as well as the individual perspective they likely reason from. In the case of the cochlear implant a metaphor similar to life-death issues was encountered in the argumentation by some parents. Reinstating hearing was perceived as a rather "essential" endeavor, at least for parents of recently implanted children. We suggested that some implant teams reason along parallel lines. As such cochlear implantation may be said to be drawn into the waters of a no-lose philosophy really. Nevertheless, the previous section illustrated how critics depict this point of view and argue that we ought to expand our benefit model beyond this prejudice-based heroism. Based on our previous discussion on scrutiny of medical procedures in general, we could frame cochlear implantation as follows.

Figure proportionality balance



Three propositions form this model We will continue to scrutinize these propositions to illustrate the fallacy of the heroic discourse in the context of cochlear implantation, explicitly based on a benefit model that feeds on the material that we discussed in the previous chapters

The state of the non-treatment alternative of Deaf culture

As we have argued, analysis of utility is rather dependent on the merits of the non-treatment alternative The positive and negative results that we seek with medical treatments only materialize in relation to the status of the non-treatment alternative As such, focusing on the state of non-intervention is rather critical and instructive in the context of cochlear implantation

Based on a no-lose philosophy, implant teams sometimes silently seem to suggest that the state of non-intervention is as nihilistic as the life-and-death context from which it originates In other words, the state of non-intervention is considered so grave and so depleted of positive attributes that it legitimates the procedure regardless of its own merits, regardless of possible mediocre positive outcomes and the fate of failures that still need to be discussed This may be comprehensible if the "interest" of deaf children is restricted to speech, yet as we argued such a view is rather deficient speech is a valuable asset to a child's best-interest and for very specific reasons, but it certainly is not *defined* by it Unless implant teams are at fault of the kind of "professional deformation" that we discussed previously and equate spoken language to best-interest, the "heroism" that surrounds cochlear implantation and the silent nihilistic portrayal of the non-treatment alternative that shapes it, must rely on common prejudices about the burden of untreated deafness that we discussed in chapter three As Reinders states in the context of genetic disease

> Public debate on human genetics has been largely shaped by the question of what this new technology has to offer with regard to genetic disease The apparent assumption behind this question is that to be burdened with a genetic disease is to be burdened with a life that one would rather avoid Accordingly the medical uses of gene technology are perceived in the context of helping people avoid a cause of serious suffering in their lives [ ] The presumption of suffering in this context may depend more on beliefs and attitudes that prevail in liberal society than on informed views about the lives of disabled people (Reinders 2000, 161)

Lay people, such as physicians, audiologists and inexperienced parents, likely share a similar intuitive conviction on the burden of deafness, which makes it not so much of a surprise that a discourse of "hopelessness" and "sadness" makes headway when cochlear implantation is discussed (Reinders 2000) Though these emotions are rarely made concrete, one could suggest that what is initially considered at stake is mainly a deaf person's socio-emotional interests or his or her potential to lead an emotionally fulfilling

life As we discussed in terms of the "exemplar of silence", the lack of access to sound and spoken language is in itself postulated to rule out such a life As we have shown, inexperienced parents indeed had trouble envisioning *any* positive future at all, which in part triggered them to adhere to the thesis that "any gain" in hearing is worthwhile Yet this view was rectified rather swiftly in spite of the fact that no advances were made in terms of access to sound Moreover, the narratives by non-speaking Deaf adults also strongly discredit the thesis that not hearing in itself fundamentally compromises socio-emotional interests Reinders states that

> These people [mentally disabled-ccw] have their own set of values based upon their particular convictions and beliefs about living a disabled life [ ] People with impairments can actually feel quite well and enjoy their lives" (Reinders 2000, 12/54)

If we uphold the thesis that cochlear implants are valuable because they facilitate a deaf child's future "human relation" and "opportunity" interests, the non-treatment alternative is not nihilistic either While cancer patients indeed have no physical future to realize any existential life or interests if untreated, non-implanted deaf children *do* have an available future, be it not the same future that hearing people seek, in which they can express themselves and establish their interests Though the Deaf culture path eventually does have significant liabilities that must be taken into account, it does at least provide deaf individuals an ecology in which they can materialize their current socio-emotional needs as well as their future human relation interests (Buchanan 1989) The liability of restricting an individual's social window, his or her freedom to choose a socializing context, is of concern but the ease of communication is a definite positive note Moreover, as the radical communitarian arguments suggests, it grants deaf children a context to express their future opportunity interests as well The restrictedness of this environment will co-depend on the quality of education, which parents suggest is sub-optimal at this point, and the results of the political Deaf culture campaign If we measure outcome based on the situation as-is, it seems likely that cochlear implantation has more potential than the non-treatment option to realize the liberal values that we discussed in chapter seven Yet advocates of the non-treatment option aim to realize better education, higher education availability, increased Sign translator availability and affirmative action to allow the deaf job opportunities congruent with their skills If these goals are indeed realized, the appraisal of the non-treatment option would significantly increase even though it would still suffer from the liability of being a rather exclusionary option as well as one which makes the deaf dependent on society, unless the latter would be changed fundamentally (Reinders 2000) Hence, the alternative of non-treatment may not be optimal or perfect, but it certainly is not as nihilistic as non-treatment in the case of life-saving procedures As such, the non-treatment alternative cannot be disregarded and a sincere comparison with this option in terms of the realization of interests seems rather reasonable

On the other side of the coin there is enough reason to question if the Deaf culture alternative is so superior in its ability to cater to a deaf child's best-interest that we should a priori discount cochlear implants as a nihilistic option. While autobiographical work by people with disabilities indeed suggests that Deaf culture contributes to deaf adults' socio-emotional or human relational interests, it does implement distinct liabilities as well. In spite of the communitarian critique, these liabilities are most likely to be in the field of opportunity interests. By current standards, not being able to communicate in spoken language will likely compromise a deaf individual's opportunity outlook. Successful implantation can at least theoretically lead to an increase in the "opportunity range" (Daniels 1985; Loewy 1990). We agree with Gutmann that since the basic liberties or opportunities of an individual are at stake we should be reserved at least (Gutmann 1994). Yet even in terms of socio-emotional and human relation interests we would advocate prudence. As we argued, in spite of self-reported agony there is good reason to question if a non-Deaf culture life is the irrevocable hallmark of emotional suffering. The fact that Deaf adults claim to lead happy and fulfilling lives rebuts our prejudiced view on the state of deafness but it does *not* imply that they would necessarily lead unhappy lives if they had to do without Deaf culture. The fact that Deaf adults believe that Deaf culture best serves their human relation interests may be true but this does not automatically transfer to the case of young deaf infants. To apply a biography in such a retrospective fashion is not without problems as we argued in chapter seven. First and foremost, because such an "optimizing" view would overcast the other interests that are at stake in the case of young deaf children. Deaf adults reason from a specific and rather irrevocable context in which opportunity interests and human relational interest have reached a certain end point. They have been socialized in the context of Deaf culture and have little option beyond that social environment. The balancing of interests that we advocated is also rather inapplicable to their situation. Choosing for Deaf culture in their case does not curtail opportunity interests; rather it is likely their best opportunity to realize these interests. Based on the "ethics of difference" one cannot reasonably expect adult disabled people with shaped biographies to make a change that is at odds with their biography (Appiah 1996). Indeed for people who have grown up with a disability the "distinction between the person and the condition argument" becomes rather problematic (Reinders 2000). As such the argument made by Tucker that deaf adults should accept an effective treatment for deafness if it were available is questionable indeed (Tucker 1998). The fact that some Deaf adults claim that they value their isolative situation positively is also deceptive to some extent. It has been found that the world of the disabled always consists of two worlds, that of the "disability" and that of "normal" society (Wever 1997; Van Noort 1999). Even though many disabled come to find satisfying and fruitful lives with their handicap, at times many continue to long for resolution of the disability and a more symmetric relationship with normal society. Though some have contested that this is not the case for pre-lingually deaf adults, we have reservations about this assumption (Lane 1998). In-depth interviews with adult deaf individuals reveal a similar trend (Van Noort 1999).

The state of cochlear implant successes

As our previous argument suggests, the state of cochlear implant successes consists of several variables, namely the magnitude and probability of positive outcomes and the magnitude and probability of negative outcomes. As we argued, the no-lose philosophy of life-saving procedures is derived from the biased assumption that saving biological life is self-justifying, in light of the abysmal consequences of the non-treatment alternative. Biological life is a prerequisite for any kind of existential life and as such should be allocated a "perfect score" in terms of the magnitude of treatment outcome. Though we cannot quote any implant team on this, the heroics surrounding cochlear implantation suggest that it too alludes to this moral space. If we re-instate hearing in a deaf child, we should consider the magnitude of this outcome to be sheer enormous, and as such should allocate a "perfect score" as well. Moreover if we look at how implant teams have discussed the merits of their treatment, it appears that the magnitude of possible negative outcomes are considered rather minimal, as they have mostly been discussed in terms of process or treatment related issues such as post-operative infections (Luetje 1997; Cohen 1997; Cohen 1994).

Yet in order to make a fair assessment we need to know more precisely how positive and negative outcomes are defined. Based on the elementary benefit model of cochlear implants, audiometric gain and advances in closed- and open-set speech recognition are the most likely candidates in terms of positive outcome. Yet the parallel with life-saving procedures that we just touched upon comes to an abrupt halt here. Life-saving procedures can retreat into the questioning but nonetheless hard to refute assumption that, barring comatose and severely demented or retarded patients that lack a self and hence lack the basic elements that constitute an existential life, biological life is a prerequisite for any kind of existential life and as such is self-justifying as a treatment outcome. Yet this rhetoric hardly applies to the case of audiometric gain or open-set speech recognition. As we argued, the value of statistical improvements in audiometric gain in itself does not translate into a child's best-interest automatically, let alone a self-justifying form of "perfect-score" benefit. Rather, audiometric gain is of potential value because it is considered an objective confounder of spoken language skills and ultimately because of the contribution spoken language is postulated to make in terms of a child's future opportunity interests. While we would not want to deny that audiometric gain in itself makes a contribution to benefit, we would argue that in itself this contribution is rather modest. Though comparison to self-reported benefit in post-lingually deaf implant recipient may suggest otherwise, we have no data to support the thesis that sound perception in itself contributes much to a pre-lingually deaf child's best-interest. The fact that many pre-lingually deaf adults do not use their hearing aids outside of communication contexts and the tentative evidence from this study that some children also preferred their implants in communicative situations, adds preliminary evidence to this. Finally, we repeat that context is essential in determining the magnitude of benefit and would suggest that the context of post-lingually deaf adults is *not* synchronous to that

of pre-lingually deaf children. The "problems" that a pre-lingually deaf child faces are different in class and magnitude. The central problem of post-lingual deaf individual may be said to be difficulty in communicating in a communication mode that is in itself intact, perhaps added by a sense of longing for a return of environmental sounds. From this perspective, a technology that assists them in improving these problems may be attributed a high magnitude of benefit. The central problem faced by a deaf child however is his or her hugely inhibited ability to master spoken language, acquire knowledge and the resultant seriously compromised opportunity to establish his or her best-interest. Not being able to hear birds and the doorbell are rather "secondary" problems in this respect. As such it seems unreasonable to assign a large magnitude of benefit to an intervention that leads to the latter. If implant teams persist to focus on audiological gain, environmental sound awareness or closed- or open-set speech advances, they risk that their outcomes are allocated a rather mediocre score in terms of contributing to utility, which in turn will lead to higher demands of probability of success and low magnitude and probability of liabilities. If cochlear implants lead to spoken language skills, the magnitude of benefit is likely to increase. If it leads to significant contributions to a child's future opportunity interests, it becomes even larger. Callahan defines a 4-item checklist to which "level 6" treatments, such as renal dialysis and organs transplantation, must be subjected (Callahan 1994). If benefits to a child's future opportunity interests materialize, cochlear implants appeal to two of these standards in particular, namely 1) the "promise of relieving long-term care demand" by "promoting independence" and "relieving institutional burden" and 2) the "promise of meeting basic human [functional] needs" by "restoration of basic function necessary for daily living". So, the utility of cochlear implants reaches its maxim in terms of positive outcome if it can make a contribution to a child's future opportunity interests.

Should we as such attribute a "perfect score" in the theoretical case that the technology would succeed in this respect? We feel that this is not necessarily the case. While biological life is an undisputable prerequisite of any kind of existential life and has distinct dichotomous qualities (biological life is either present or it is not), neither of these traits is applicable to the "future opportunity interests" of a deaf child. The notion of future opportunities represents an existential, though widely shared, value in itself. As such it is of great importance to our lives, yet not in the same coercive way as biological life is. Life without or with diminished liberal future opportunities *can* be lived and does not nullify humanism as the case of persistent vegetative patients perhaps does. Moreover, future opportunities are not dichotomous in nature but rather represent a continuum as we argued in chapter seven (Musschenga 1987). This suggests that we should allocate magnitude appropriately, hence in a rather scale-like manner. As such we would conclude that even if cochlear implants were perfect and would "normalize" a deaf child in terms of his or her future opportunity interests, a "perfect" and self-justifying score is not in place.

A next issue that we should discuss is the *probability* of positive outcome to materialize. So far we discussed probability from a theoretical perspective. However interesting this may be, we must ultimately know how implanted children actually do in these terms. So how are the children of our respondents actually doing in this respect, as described in chapter six? Where should we allocate them on the scale of future opportunity interests? To make such a judgment is by nature tentative, since the biographies of these children have not been completed, which implies that we can at best try to make projections based on children's current functioning. Given the protracted revalidation trajectory it seems fair to restrict our view to "experienced children", even though this implies a selection bias because of the non-representative traits of this group. In chapter six we defined this group as children with at least 18 months of cochlear implant experience (n = 11).

Our material clearly showed that the variability was wide indeed. In terms of subjective measures we found that about 50% of these children mastered "excellent" oral-aural skills. These excellent skills may indeed yield a significant benefit in terms of a child's future opportunity interests. The fact that all but one of these children actually attended mainstream education without a Sign translator is in support of this hypothesis. Yet the other half of the group mastered "marginal" spoken language skills. While this yielded a benefit in terms of being able to communicate with family, friends and neighbors it did not directly materialize as a benefit in terms of educational options. Though our data seem to suggest that quite a few implanted children are well on their way to *cash-in* on the promise of enhanced future opportunities interests, we recall that critics question this. Critics have attested that implant may actually sacrifice a child's future opportunity interests as they postulate that it will hold back cognitive development and as such a basic prerequisite to develop an autonomous self.

As we argued, the no-lose philosophy depends both on the assumed self-justifying nature of the outcome of medical treatments in light of the non-treatment alternative as well as the assumption that liabilities are negligible vis-à-vis this overwhelming outcome. Yet we criticized this view in the context of life-saving procedures and suggested that we need to consider negative outcome in more detail. In this section we have applied this critique to the case of cochlear implants as well. We suggested that the non-treatment is not as abysmal as suggested and argued that positive outcome is unlikely self-justifying in itself. This implies that we need to look at cochlear implant liabilities in more detail as well. What are the liabilities of cochlear implant successes, what magnitude should we allocate to them and how likely are liabilities to occur? Cochlear implant teams have inventoried liabilities in terms of process or treatment-related complications mostly. The complication rate of the procedure is low, which as such may be argued to add to the legitimacy of the procedure. Yet we have advocated a broader perspective on the outcome of medical procedures and this includes negative outcomes as well. One possible liability raised by critics, is that to make the implant work parents and implant teams are likely to ignore a child's current socio-emotional interests. To make cochlear

implants work, a large and enduring investment is required by both parents as well as the implanted child. Without speech training, a stimulating home environment and resilient and perseverant parents implants are unlikely to yield success in terms of a child's future opportunity interests. This implies a significant investment over the course of many years. It has also been suggested by some that to make implants work, a deaf school environment may not be suitable, which clearly caters to the concerns that critics have raised. Holden-Pitt found that implanted children were more likely to attend oral institutions (36% versus 8% of controls) and were less likely to be approached through a combination of Sign and speech (58% versus 82% of controls) (Holden-Pitt 1997). Indeed we found that many of the most successful cases were alumni of an oral school for the deaf or were mainstreamed early on. Though we suggested that there is no compelling evidence that links socio-emotional well-being to early spoken language exposure, we do feel that this is an issue of concern that should trigger implant teams to include socio-emotional parameters into their follow-up. Another central liability that critics have confronted us with, it the possibility that in spite of making the best possible advances in terms of spoken language skills, successful cases will still fail to instate their future socio-emotional interests in hearing society while we have deprived them from the means to engage with deaf peers instead. Indeed even the most successful children in our study continued to experience difficulties, mostly in terms of their human relations interests. This finding has also been reproduced by Bat-Chava in terms of deaf-hearing socializing characteristics (Bat-Chava 2001). It seems reasonable to assume that even the most successful implanted children will continue to encounter social and societal problems as their lives advances. Though it is arduous to do so, based on the biography of successful adult deaf individuals one may hypothesize that these difficulties will continue into adulthood. Though we questioned the validity of these suggested liabilities, we do feel that they raise some rather crucial points that counter-balance the focus on treatment-related liabilities that has characterized most of the assessment trials to date. Though we lack empirical evidence to substantiate many of these suggestions, mostly due to the design of implant assessment studies themselves, we feel that there is enough circumstantial evidence to abandon the thesis of "zero" liability. Though we do not know exactly what liabilities implants yield, we do know that they may yield considerably more than treatment complications alone.

The state of cochlear implant failures

As we previously argued, the condition of "treatment failures" is rather crucial in assessing the utility of medical treatments. This is most important in the case of "low-chance" treatments since they by definition produce rather large numbers of people who have to endure the liabilities of a treatment without ever being able to enjoy its benefits, which as such is likely to pitch the proportionality balance away from such treatments. While failures are readily recognizable in the case of life-saving procedures, this is not so self-evident in cochlear implantation. As a logical extension of the debate over what

comprises "success", a quarrel has arisen as to what constitutes a "failure" really (Tobey 1994). Yet before we can evaluate the state of cochlear implant failures we must be clear about our concepts.

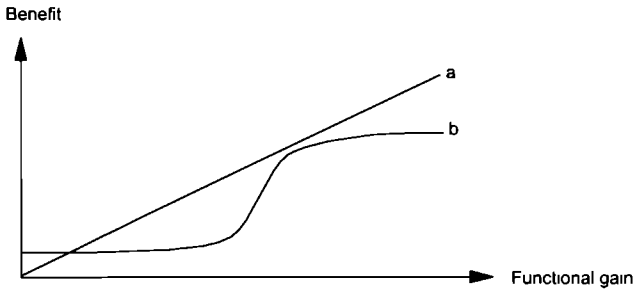
Rose has argued that "non-use" is ultimately the best measure of cochlear implant failure (Rose 1994). We mostly agree with this view and do not share the rejection of this measure as a hallmark of failure (Tobey 1994). However, opponents of non-use as a hallmark of failure have claimed that we ought to separate failures due to the device itself from failures due to "other" circumstances.

> Is the failure to continue wearing an implant due to inadequacies associated with the device or inadequacies associated with the environment where the device is worn? (Tobey 1994)

Certainly, non-use is modulated by more than the yield of the implant in itself, such as the inadequate oral-aural stimulation offered by some deaf schools, peer pressure and personal factors. Yet by the "intention-to-treat" paradigm we should accept the potential of these factors to modify "compliance", rather than use it as an apology in hindsight (Hollis 1999). Though the intention-to-treat paradigm originates in the context of randomized clinical trials, some of its logic is applicable to our case as well. As Hollis states, an intention-to-treat outlook gives "a pragmatic estimate of the benefit of a change in treatment policy rather than of potential benefit..." and as such is more fit for "pragmatic trials of effectiveness rather than for explanatory investigations of efficacy" (Hollis 1999). From this formulation it appears that Tobey fails to differentiate the two aims that Hollis outlines, confuses appraisal of a *scientific effect* from the pragmatic concept of *benefit*, which we argued to be central to our analysis of utility. Hollis' differentiation implies that a procedure can be technically or medically efficacious and pragmatically non-effective at the same time. If we, as we clearly did, uphold that medical procedures are not simply aimed at a scientific effect but should translate into benefit the discrepancy between the two becomes intelligible as well as the need to acknowledge non-compliance for the purpose of evaluating utility (Schneiderman 1990). It may well be that the counter-intuitive finding of non-compliance in the case of treatment with proven scientific effect of efficacy springs from the potential divergence between "effect" and "benefit". It seems that almost any other explanation must lead to a paternalistic view on non-compliance, a view in which non-complying patients are depicted as being ignorant of their "true" best-interest. Ignoring failures and morbidity or placing the blame for failure beyond the treatment itself, for example on the assumed non-compliance of the patient, should be avoided. Verbrugh depicts this as characteristic for the "pure science ideology" of medicine. Illich confirms this and states that the "depersonalization of diagnosis and therapy has changed malpractice [such as treatment failure-ccw] from an ethical into a technical problem" (Illich 1975). Verbrugh feels that this ideology has no place in medicine since "science, medical science in particular, depends on its applications" (Verbrugh 1972 – translation ccw). This is true for cochlear

implantation as well to deny that adult non-use constitutes failure is to deny adult deaf people the respect to make a fair cost-benefit analysis and to fall victim to overt paternalism Ultimately the renunciation of non-use as a measure of failure thus seems to thrive on prejudice or perhaps professional deformation The former alludes to the prejudiced pitiable view on deafness as discussed is must be terrible not to hear and as such any hearing is beneficial, something which Deaf adults sadly enough fail to recognize The second perhaps alludes to the perspective of oral deaf teachers, who know that hearing thresholds are a crucial determinant of the ability to learn to speak, which in turn is crucial to improving one's social outlook If this truism is expanded indefinitely it becomes incomprehensible indeed that anyone would not use an implant This is not to say that we should be ignorant to conditions that negatively impact compliance, certainly not in a case where the magnitude of potential benefits are considered high Indeed we should aim to improve such conditions, yet that does not undo the judgment of non-use as an important hallmark for failure We can even proceed beyond the definition of non-use as a hallmark of failure Since success and failure are inextricably related, we could argue that those implanted children that do not realize any measurable benefit in terms of their future opportunity interest may be considered a failure, regardless of the question if they actually use their implant

Yet to date there is little known about the probability of non-use in the pediatric implant population, perhaps as the result of fact that very few implanted children have matured into adulthood Christiansen suggests a very low rate of non-use, yet his study is limited by a relatively short follow-up (Christiansen in press) In a review of 816 implanted American children and adolescents, Holden-Pitt reports a non-use prevalence of 13%, though she also reports a rise of non-use during early adolescents while only a small proportion of her sample had actually reached that age (Holden-Pitt 1997) To make an estimate on failure is thus by definition as tentative as to predict success Inversely to our reasoning in terms of success, one may argue that experienced children that lag behind in their oral language skills are at risk of becoming non-users in the future Regardless of the question if they continue to use the implant, the promise of enhanced future opportunity interest may be said to be at least feeble We would suggest that a lack of benefits in these terms is a likely hallmark for the final proof of failure, namely non-use One may argue that the above is fallacious since "optimal effect" need not be required to yield benefit and to safeguard cochlear implant use on the long run Since we said that positive outcome in terms of future opportunities is likely to be scale-like, the inverse must also be true Hence, some hearing or spoken language skills may be considered as success nonetheless Yet the pitfall of implants is that it may prove that certain sub-optimal effects may just not be enough, hence undermining the argument that any objective functional "improvement" will also actually be experienced as beneficial by the deaf individual on the long run While a sliding slope (curve "a" in figure below) of success may be reasonable from the point of view of the implant scientist, a more or less "on-off" model of success (curve "b" in figure below) may prove more applicable in the case of the implanted person him or herself



While we continue to argue that a scale-like model of success is valid, its validity may be limited not only by a "ceiling", but also by a "floor", something parents seemed to agree with as we discussed in chapter six. The former was discussed in terms of cochlear implant success, as we argued that implant success is unlikely to be "optimal" in terms of "normalizing". The latter implies that below a certain bottom threshold of benefit, non-use may be a likely outcome on the long run. In social terms a sliding slope model does not appear to fit reality. In this sense, a comparison with the well-known issue of low hearing-aid use by deaf adolescents and adults may serve as an example (Markides 1989). Though some implanted children will likely benefit in terms of their future opportunity interests while still functioning in Deaf culture mostly, there is a likely limit to this line of reasoning. There is likely to be a "bottom" threshold, below which benefits in terms of participation in hearing society are simply to meager and retreat in Deaf culture is a likely outcome. The continuous use of the implant for such individuals is unlikely, given the low yield of benefit as well as the low need for acoustical information if life is spent largely in Deaf culture. As such we feel that this "on-off" model is illustrative as it illustrates the potential inadequacy of conceiving of *any* spoken language gain as a measure of benefit.

Yet the presence of failures in itself tells us little about cochlear implant utility. Every treatment has failures; some even have a significant number of failures while we still consider them useful. To access cochlear implant utility, we need to analyze the fate of failures in terms of positive and negative outcomes and establish the likelihood of these outcomes to occur. Furthermore, we must compare or balance these results with the state of children that succeed as well as the merits of the non-treatment option. Regarding positive and negative results in light of a child's best-interest we can also only proceed tentatively. Compared to successfully treated children, it appears logical to conclude that positive outcome is rather low in treatment failures. Again, one could argue that the sense of "at least we tried" counts as a benefit, yet this is a parental benefit mostly. One could also argue that the implant experience in itself somehow counts as a positive outcome. Even though it is conceivable that implanted "failures" benefit from for example the enhanced challenge that they are exposed to as some parents argued, in general this

position seems somewhat far-fetched or at least seems unlikely to yield benefit of a significant magnitude. As such we would suggest that the magnitude of positive outcome in implant failures is rather limited. In terms of negative outcome, judgment is perhaps even more difficult since it is highly dependent on context. If we look at what critics have had to say about this, about the same liabilities arise that we discussed in terms of successful children. Hence, due to the cochlear implantation procedure failures have been exposed to surgery and the subsequent sacrifices made in terms of Sign language and Deaf culture without coming through with benefits in terms of a child's future opportunity interests or future socio-emotional interests. Critics fear that implanted "failures" will likely be exposed to spoken language and educational mainstreaming challenges while they lack the skills to make these challenges reasonable from an emotional perspective, hence sacrificing their current socio-emotional interests and sowing the seeds of future emotional distress. Critics fear that cochlear implantation will seriously jeopardize children's future human relational interests in the process, since these children will be withheld the social and linguistic skills required to function in Deaf society. Since failures will also fail to materialize their human relation interests in hearing society, these children have been postulated to be predestined for a "culturally homeless" existence (Lane 1997). Finally, these children's future opportunity interests are assumed to be curtailed, since the effort put into the implant *must* sacrifice their potential to develop in a Sign language environment. As such one may reason that negative outcome is significant indeed. Yet as we have said, the magnitude of these liabilities is dependent on context at least to some degree. Ultimately it seems that to give implanted children a fair chance to succeed, their opportunities to enjoy the benefits of a Sign environment must be curtailed to some extent. Especially if implanted at a very young age, as is becoming more and more common practice, the choice for an implant may coincide with language and educational choices and may hence stimulate lower degrees of Sign language proficiency in spite of our finding that most parents found this medium highly valuable during the early childhood years. Yet unless this is done ruthlessly, the magnitude of this liability does not *have* to be as dramatic as depicted. Our study clearly showed that parents were aware of this impending threat and continuously re-examined their situation. Most parents continued to use Sign language even if their child was doing well in spoken language terms. Furthermore, the looming threat of cultural nihilism is strongly dependent on the way that Deaf culture defines itself. If Deaf culture defines itself in terms of an exclusively Sign language society and an exclusively inward-oriented society, the risk of excluding implanted failures may indeed materialize.

Balancing success, failure and the non-treatment alternative

It seems fair to assume that cochlear implant successes emerge favorably in comparison to the non-treatment option, though the extent is dependent on the magnitude of success. Cochlear implant failures however will unlikely surface favorably and may even be argued to be at risk of a negative judgment, even though the magnitude depends on local

context. As we have argued previously, the inventory that we presented in the previous sections can hardly be "added-up" in some sort of arithmetic equation. Still some questions do present themselves. Similarly to our argument in the context of life-saving procedures, the thorniest question is perhaps how we are to balance the favorable position of successful children to the lot of those that fail. Given the moderate weight on both sides of the equation, probability becomes rather crucial. What if only 20% or 30% of implanted children would ultimately succeed?

Would the accomplishment of successful cases not overrun the lot of those that fail? This question is related to arguments in favor of acceptance of low-chance life saving procedures as well as the previously mentioned "no lose philosophy". In the case of oncology and neonatology it is rather difficult to provide arguments against such a notion. Failures in oncology are patients that will succumb to their illness, a lot that also would have waited them if not treated. As we illustrated, ethicists have therefore focused on the treatment related suffering that failures are put through, potentially counterbalancing the success of the few that do survive. Yet, given the short time-span during which failures are exposed to these additional liabilities and the generally moderate liabilities of those treated successfully, the balance will often still favor the treatment side. In this context the case of neonatology is rather different. While as the result of the very young age of the subjects, treatment failures are likely discounted even more pronounced in this setting, the potential severity of comorbidity in successfully treated newborns is rather conspicuous. As such ethicists have focused on the long-term liabilities for those preterms that do survive.

In the case of cochlear implants these arguments are enlarged. Contrary to oncology, treatment failures cannot be discarded. The liabilities induced by treatment failure must actually be endured during an entire life span. While the magnitude of these liabilities may not be as large as the liabilities of successfully treated premature infants, failures do influence procedure statistics. As we argued, the "success" of the optimal cases is not trouble free either, therefore lowering the impact of these cases on the final balance of proportionality. Also, while the magnitude of benefit is likely high it certainly is *not* optimal and self-explanatory as we have shown to be the case (though rhetorically) in life-saving procedures. Hence we feel it is fair to state that the success of the optimal cases does not a priori legitimize the liabilities of those that fail, certainly not if failures outnumber successes. As such one could reason that low probability of success significantly affects the utility of a procedure such as cochlear implantation. Hence as a reply to Tobey's question "should a young child be denied a cochlear implant on the off-chance he or she may elect not to use it 10 years later?" we would suggest that this *can* be a logical deduction indeed, though we cannot jump to a conclusion based on this information alone (Tobey 1994). An end appraisal of the utility of cochlear implantation does not only depend on failures. Rather we should determine what the likelihood of failure is as well as the magnitude of its consequences in terms of a child's best-interest

and balance this vis-à-vis the benefits of those that succeed while considering the merits of the non-treatment alternative.

As we have argued, the probability of failures to occur is very difficult to determine. Even though we have few hard data to go on, inductive reasoning based on the performance of our sample and the biographies of the adult deaf population may be argued to suggest that the number of failures will not be limited to the single digits. Hence, implant teams should attempt to identify children that are likely to succeed and those that are not. From this perspective Holden-Pitt for example, clearly found a lower likelihood of continued use in children with a combined (physical and cognitive) handicap (Holden-Pitt 1997). It is highly desirable that we improve the likelihood of positive effect to occur (Buchanan 1989). Yet implant teams lack the skills to pre-determine success. The current lack of tools to estimate who will be successful and who will not, the resistance that some have expressed against such measures and the dominance of Sign language in deaf education suggests that this situation is likely to persist in the coming years. This in turn implies that the fate of failures becomes paramount for our appraisal of cochlear implant utility. If failures cannot be reduced and their numbers are likely to be significant, it becomes rather essential to reduce the magnitude of the liabilities that it brings about. The liabilities of failures can be softened if an eclectic approach is upheld.

Conclusions

As we have discussed, in many medical decisions surrounding the end of life a symbolic discourse appears to emerge as the result of the rhetoric of death. A terminally ill patient who rejects experimental therapy may, for example, be confronted with family and loved ones who are startled by such a decision (Hilhorst 2001). The decision may rhetorically be rejected as one "against life" or even of "betrayal" towards those who value and love the sick person (Musschenga 1987). In the setting of critical care neonatology, the choice to withhold further treatment to an extremely premature newborn, may encounter a similar situation. Proceeding with treatment is a likely outcome of parents' deliberation process - though some of the most controversial cases have focussed on parents' decision to forego treatment - not only because of the individual perspective from which they reason, but also because of the metaphorical implications of the decision they face (Rhoden 1986; Guillemin 1986).

Parents of a young deaf child may also be vulnerable to such a "symbolic discourse", which is however only tangentially related to the best-interest of their child. Clearly we have showed that DC-ID appeals to this discourse. We have shown abundantly how authors such as Lane have framed parents' decisions in a virtuous dichotomous framework. In this way, decisions become considerably more than pertaining to the best-interest of the deaf child him or herself – which is undesirable

(Gutmann 1996a). Rather, they become the epicentre of parents' symbolic intuitions or attitude towards their offspring: they are primarily aimed at rendering parents' moral self-view more coherent (Rorty 1996). Popular values such as "unconditional love" and "commitment" become paramount and likely influence the decision considerably. Yet as we have shown in this section, a similar situation arises in the context of cochlear implantation if benefit and hearing status are inextricably equated and upgraded in a no-lose philosophy. The probability of this to occur seems rather large, given the fact that it appeals to our common cultural prejudice on deafness. The choice for a cochlear implant may as such become a symbolic choice, in which parents express their commitment towards their child best-interest (Churchill 1994; Hilhorst 2001). By deciding for a cochlear implant, parents may be postulated to symbolically express their unconditional and self-sacrificing dedication towards their child's well-being an interest. If hearing becomes entangled in such a symbolic discourse, indeed any increase in hearing may be perceived as welcome and the choice for or against an implant becomes a non-choice really. Indeed some implant team members have expressed loyalty to such a vision.

> Given the rapid advances in the science and technology behind these devices, it seems safe to predict that failure to prescribe a cochlear prosthesis for a deaf five-year-old will soon constitute malpractice. (Loeb 1993)

If *any* gain in sound perception legitimizes cochlear implants and if failure is a priori framed against the backcloth of an "at least we tried" and "we have nothing to lose" attitude, criteria are out of reach. As such, measuring outcome becomes a "formality" so to say (Hilhorst 2001). Choices based on these grounds are questionable however, given the fact that the primary responsibility of parents is towards the well-being of their child (Beauchamp 1989b). The statement by Loeb is particularly worrisome if we consider Reinders' warnings vis-à-vis the semiotic treat that genetic screening inflicts (Reinders 2000).

Reinders' warnings

- The growing knowledge of genetic disorders will increase the awareness of the possibility to prevent birth of people with those disorders
- The increased area of reproductive choice will mean that reproduction will be perceived as a matter of choice, including parental responsibility for the birth of disabled children
- The argument claiming social support for children with special needs will be considerably weakened if there is a question of parental responsibility for their existence
- The rising pressures on national health care budgets demand that individuals be held responsible for risks they take with regard to their health
- Decisions to allow the birth of a disabled child will be seen as a decision for which people should be held accountable

Indeed one could argue that Loeb's statement proves these worries right, as he seems to suggest that in the future parents will not have a choice really. If the socio-cultural embedding of cochlear implants is that of a "miracle-cure", the chance that at least those

that positively choose against it are deprived from the means required to realize a reasonable alternative seems real indeed: "families can expect to be interrogated about their personal behaviour" (Reinders 2000). From this perspective it is easy to understand why the introduction of implants has caused some unease with parents who chose against implantation. These parents may fear that they will be "punished" for their decision in the future, a highly unwanted situation to say the least that conflicts with the ambiguous nature of the cochlear implant decision.

In this section we have advocated that we expand our view beyond such a prejudiced no-lose philosophy based on several concrete observations. First and foremost the non-treatment alternative is not nearly as nihilistic as it is in the case of life-saving procedures. Secondly, we have argued that hearing status in itself is an inadequate measure and is at risk of confusing "efficacy" with "benefit". If benefit is defined as enhanced future opportunity interests and enlarged human relation interests, a rather scale-like allocation of success materializes. Yet we have also argued that this scale is unlikely to be linear, since both a ceiling as well as a floor probably characterize it. Regarding the latter we suggested that if the outcome of the implant falls below the floor-threshold, non-use is likely to occur, which constitutes failure really. We have argued that the state of failures is potentially one of the most worrying problems if we release a no-lose philosophy and if we grant the non-treatment option the value that it is worthy of. Cochlear implant failures can potentially pivot the proportionality balance towards the negative axis if their numbers amount and if their fate is shown to be unfavorable compared to the non-treatment option. Hence implant teams should include the fate of failures into their responsibility. Failures should remain the responsibility of implant teams since the liabilities of this group strongly influence any final appraisal of implant technology. Even though we will not attempt to make any final appraisal, we do conclude that the "what if only 20% or 30% of implanted children would ultimately succeed" argument has serious liabilities and that implant teams should hence continue to make a strong effort to select suitable candidates. Implant teams should continue to follow-up their patients so to allow flexibility in approach when this is asked for, softening the "fall" of failures so to say. The "problem" is however that failures are unlikely to materialize until many years later, Holden-Pitt found a rise in non-use during the mid teen-years, and it may well be that implant teams have lost their contact with children by then (Holden-Pitt 1997). From the perspective of responsibility this is not an advantageous situation, since responsibility is best experienced hands-on.

Dutch philosopher Achterhuis has commented extensively on the debate on medical technology. He states that indeed we should scrutinize the promises of medical technologies (Achterhuis 1998). Achterhuis believes that these promises commonly go far beyond the parameters of benefit on which their marketing is based: what is promised is often a far cry from what is being measured. As we have shown, this is not different in the context of cochlear implantation. The assumed problem and misery of the deaf cannot be reduced to the decibel and thus cannot be resolved through an implant alone. It is for

now a utopia to conceive of the cochlear implant as the sole measure to reach optimum benefit for deaf children. The same is true though for the Deaf culture critique. The psychological and linguistic critiques are fruitful though in pointing out the limited scope of the medical paradigm in thinking about benefit, yet these critiques carry their own limitations and moral liabilities. Involving a deaf person in our world takes energy and deep investments, on both sides. A deaf person would fare well by learning to speak if this is of course a reachable goal. Thanks to the cochlear implant this now has become a reachable goal for some profoundly deaf children. Society should however realize that great effort from its side is required as well if we really want to make it happen, if we want cochlear implants to be a success and if we want to involve the deaf in our world. This implies that we should be wary of the risk that cochlear implants pitch our view too much towards the cure-perspective at the expense of the very much needed "care" needs of the deaf population.

> Curative medicine has a strong bias towards eradicating the causes of disease. Effective care from this perspective implies care that removes these causes, preferably as soon as possible. Such a speedy and efficient form of care is rather impossible in the case of chronic illness. (Ten Have 1998, 220 – translation ccw)

Reciprocity, one of four elements of Fukuyama's concept of social capital, may capture the balance needed to make things work (Fukuyama 1995). Communication with a deaf person will *always* remain difficult; will always require significantly more effort than communicating with a hearing person. If we want our experiment to be successful we must be prepared to go that extra mile. On a personal level, those in the direct environment of a deaf person should learn to be patient when communicating with a deaf person, should actively involve that person in our dialogues and learn some basic understanding of Sign language. On a macro level, deaf schools should work harder at developing an educational plan that is truly bicultural and bilingual and should be supported financially and organizationally to realize their plans. Higher education is still a major hurdle for the deaf. Deaf translators should be available when needed and positive discrimination should be considered.

DISCUSSION

In the introduction of this chapter we noted that in spite of the forward momentum of cochlear implantation, disagreement over the technology was rather fierce in the first half of the 1990s. In this chapter we have described the position of the opposition and determined it's position vis-à-vis the benefit model of implant teams. We suggested that the elementary benefit model of cochlear implantation is rather deficient and as such acknowledged what we believe to be the core of critics' argument. Indeed a benefit model of cochlear implantation should comply with the standards that we defined in terms of medical treatments in general. We should as such seriously look at what comprises a deaf child's best-interests, which includes a sincere inclusion of the state of failures as well as the merits of the non-treatment alternative. We should consider the probability of positive and negative results to occur and we should attempt to define the magnitude of these effects.

In general we feel that such an expanded benefit model bridges the critique, at least from the point of view of construct validity. It seems to us that at a professional level, the disagreement between medical-audiological and linguistics, psychology and pedagogy is at least in part the result of a bilateral incomplete understanding of values and concepts of benefit and due to professionalization which has almost naturally pitted medicine and linguistics against each other. Unfamiliarity with each other's positions and paradigmatic differences may explain this. Medicine is typically skeptic about the ability of social sciences to contribute to its field. Social scientists on the other hand, still seem to retreat into an outdated caricature of medicine. As in the 1960s and 1970s, linguists and psychologists are sometimes presenting themselves as a "humanist antidote" to the intrinsic reductionist mechanical views of biomedicine. Yet it remains to be seen if indeed they are more holistic in their perspective or represent a different fragment of truth which complements rather than contests the medical view. The answer to this question depends in part on how we define the benefit models of these professions exactly. If we limit the medical benefit model to the decibel it seems logical that the perspective presented by Deaf culturalists presents a more detailed concept of benefit. Yet if we expand both benefit models into their concepts of language and implicit social and cognitive promises, we do not see exactly how the psychological perspective is more humanist than the medical-audiological model -- rather they seem to represent the ambiguity in contemplating benefit for profoundly deaf children.

Though *extreme* Deaf culturalism will likely continue to disagree with the content of this benefit model, we suggested in chapter seven that such an ideology entails serious liabilities that we cannot dismiss. Yet as we also argued, if the concerns raised by Deaf culturalism critique are conceived of as arguments rather than a rigid ideology, they materialize as rather significant. If Deaf culturalism is perceived as a counter-discourse that aims to call a halt to the no-lose philosophy that threatens to overrun the cochlear implant practice, their role deserves serious attention indeed. If Deaf culturalism is

perceived of as a pragmatic discourse very much in accordance with a deaf child's interests, which we suggested it most likely is, its arguments deserve to be incorporated into our appraisal of the utility of cochlear implantation As such we would propose that the suggestion that the cochlear implant controversy represents irreconcilable differences in values is generally incorrect Rather the promotion of this suggestion through the promotion of radical Deaf culturalism more likely represents a *strategic* effort to counter the massive appeal of a no-lose philosophy given our cultural prejudiced view on the state of deafness

The possibility of a conflict of interest was touched upon as we suggested that what benefits Deaf adults does not necessarily have to coincide with what will benefit deaf children in the future We also suggested that some Deaf culture advocates might actually be guided by the precarious position of Deaf adults In modern day society a scarcity of resources is a given and the paths of self-interest of young deaf children and the adult Deaf population may well be divergent in this sense Given the fact that the deaf debate has been framed in the domain of cultural minorities, possible *individual* benefit of an implant may become juxtaposed to the benefit of Deaf culture *as a whole*, as this culture will potentially suffer as the result of a successful implant program (Lane 1992, Taylor 1994a) The current adult Deaf population is likely to benefit more from a "politics of recognition", both in material as well as non-material terms – as we discussed in the previous chapter Regarding the former, limited resources may imply that money put into cochlear implants will be taken away from services such as Sign translators and improving deaf education, certainly if we consider that these services consume large amounts of finances Regarding the second cochlear implants may harm the newly found sense of positive awareness that the recognition of Sign language has brought Deaf adults As we have stated elsewhere, cochlear implants are at odds with the new self-awareness of the signing Deaf population Over the past decades a strong effort has been made to meet Deaf people, in both a materialist as well as non-materialist sense Sign language has been withdrawn from the shadows of shame and resources have slowly been made available In a non-materialist sense, cochlear implants represent a breach with these efforts cochlear implants may hence "reinforce negative attitudes toward disabled [deaf-ccw] people in our society" (Reinders 2000) As many anecdotes attest, signing Deaf adults perceive of implants as a *slap-in-the-face* that disengages their newly gained sense of self-esteem Worse yet, implants may represent a breach with the material efforts as well since they may pitch the socio-cultural away from providing the very things that Deaf adults benefit from If Sign language is overcast by stories of implanted children who have mastered speech, provision of fundamental resources such as Sign translators and improved sign-based education may suffer Furthermore, some have argued that implants may even "eradicate" Deaf culture (Alden 2001) While we do not see how cochlear implants lead to dissolution of Deaf culture, the drawback is that indeed, as some have criticized, the Deaf culture option really becomes an exit option if cochlear implantation succeeds This is certainly true from a semiotic perspective Yet it may also imply that Deaf culture will become reserved for the "less talented" deaf

individuals We agree with Reinders that those involved with cochlear implants should seriously take this at heart "we need to ask whether using genetics [cochlear implants-ccw] for reasons of prevention may affect the social position of the disabled in such a way that their interests are seriously damaged either now or in the near future" (Reinders 2000) Not only Deaf adults are potentially affected by the potential redistribution of funds and the negative impact on Deaf people's identity, so is an entire generation of deaf children that *missed the boat* so to say Parents of children roughly born before 1990 did not have implants available to them and many of them chose for a full Sign language approach to cater their child's best-interest Many others continued to choose for a Deaf culture path in spite of the availability of implants Yet if we adhere to our discussion in this chapter, cochlear implant failures too may join the ranks of those that may be victimized by the forward momentum of cochlear implantation and we argued that implant teams are responsible for the fate of their failures to some extent

Nonetheless, the potential divergence in interest between young deaf children and Deaf culture is an issue that remains unsolved in this thesis Should we incorporate the fate of Deaf adults, Sign language deaf children and cochlear implant failures in our appraisal of cochlear implant desirability? We questioned the legitimacy of allowing Deaf adults to "bargain" on the best-interest of deaf children Allowing this would entail that a perpetual circle of moral wrong threatens to establish itself, given the larger vote of Deaf adults in the equation Moreover it could imply that we may reach some procedural consensus that is a far cry from a rational consensus (Guttman 1996) Majoritarianism would result in an awkward situation here Given the large number of Deaf adults relative to the group of existing potential cochlear implant recipients, allowing strict majoritarianism would principally make change in favor of future generations impossible Children would be framed opposed to the adult Deaf population in a conflict over funding and semiotics and would be predestined to surrender Indeed Bertling feels that this is already the case and feels that "sacrificing children to preserve the interests of a select few is asking too much" (Bertling 1994) As we have shown, some parents shared this concern as well Nonetheless, the problem remains and cannot be discarded The legitimacy to include conflicts of interest is advocated by Reinders in his writing about the role of medical genetics in the case of mental retardation

> If there are serious reasons to think that the new technology will have deleterious side effects on the lives of disabled people and their families, then it is a question of public responsibility how to control these effects (Reinders 2000, 8)

As we argued, we agree with Reinders in this context as we share his concern over the potential impact that cochlear implantation may have on the fate of many "actual" Deaf people as well as quite a few "future" Deaf people Yet the question remains how we ought to respond, by which means we ought to "control" potential negative impact Though we feel that we ought to respond in some way or another, we also share Warnock's view that such a response should preferably not lead to the exclusion of a

technology that can potentially improve the fate of deaf people considerably (Warnock 1993). We agree with Gutmann here that pragmatic majoritarianism is not an acceptable solution here since a majority vote alone cannot legitimate an outcome when the basic liberties or opportunities of an individual are at stake (Gutmann 1996a). While we greatly regret that upholding cochlear implantation will irrevocably invoke at least semiotic or emotional damage to Deaf adults as well as future generations of Deaf children, we do not feel that this is necessarily sufficient to override the interest of deaf children.

Yet as we suggested in the previous section, this is not to say that we should "surrender" to a no-lose philosophy and implant *all* deaf children. Cochlear implants feed on an intuitive worldview of deaf children that is overly dreadful and unfounded. Furthermore, the discourse surrounding the implant often represents an exceedingly simplistic and optimist solution for the vast real-life problems that the deaf face in our society. While Deaf life fails to realize some of the goals that we value in liberal society, it provides certain advantages as well. Some of these advantages are highly theoretical, based on non-empirical assumptions or even dependent on uncertain social and political change. Yet others are rather concrete and cannot be dismissed too easily. Regarding the latter, the non-treatment Deaf culture alternative certainly provides concrete advantages for the young deaf infant. Sign language facilitates language acquisition and greatly enhances early parent-child interaction. As the lowest-threshold language for deaf children, Sign language is the easiest medium to acquire knowledge about the world, at least during early childhood. Furthermore, the protective deaf school environment meets the real life limitations and needs of deaf children. Socializing with peers is smooth and effortless contrary to a mainstream educational setting, which remains difficult even for those successful after cochlear implantation. At least in theory the strategic Deaf culturalist path is a viable one and we should be careful not to advocate cochlear implants because deaf education as-it-is has failed to realize the goals stipulated by Deaf advocates such as Alden (Alden 2001). On the other hand, as we discussed in chapter five and seven, the Deaf culture discourse ignores central values and the potential of deaf people to realize these. As we have shown in chapter seven, it appears that the dominant care-ideology is "borrowed" from the case of the mentally disabled all too easily. In practice it seems that deaf people are not so much morally withheld these opportunities based on a civil rights discourse. Rather it seems that it is pragmatically assumed that the chances of success occurring are too slim and that the liabilities involved are too great. These latter assumptions seem to be derived from the case of the state of the adult Deaf in society today. Yet neither the historical failure of most deaf people to succeed nor their objectified psycho-emotional risk can be extended to the case of our modern deaf population uncomplicatedly.

Ignoring the difficulties that deaf children encounter in an oral environment and ignoring the social problems that even the most successful oral adolescents face, is to ignore some elements that make up the real world in which parents have to make their decisions. Ignoring the potential of individual deaf children, their enhanced resilience

and supportive family environments achieves something similar. The decisions parents face when confronted with a deaf child are very much embedded in real life and as such are not unlike those that parents of non-handicapped children face. The values, questions and problems they face are rather similar to those encountered in all parenting, as we have shown in chapter five and seven. This is illustrated for example by the ongoing educational debate: some parents feel that even regular schools have become too child-centred, have become too focussed on affective well-being and as such ignore children's capacity to learn as well as the joy they can derive from challenge (Vermeulen 2002). As such the consideration of a cochlear implant is not an anomalous contemplation, but one very understandable indeed. The same is true for the decision for Sign language and the decision to forego with implantation in favor of Deaf culture instead. A remarkable finding in this study was that, on both sides, parents expressed sympathy for each other's decisions and expressed that they could conceive of situations in which they would have acted differently, which seems to suggest a strongly pragmatic position. What these parents aim to realize for their deaf offspring when they choose for an implant can hardly be repudiated unless a hard-line Deaf culture discourse is upheld. It also materialized that these parents cannot be labelled as inflexible or blind in their aims. Concerns over the success of their decisions remained, as well as contemplation of alternative scenarios even in the most successful of children. As such we repeat the conclusion that parents of deaf children stand in the real-life middle of two conflicting abstract theories or ideologies if you will.

Over one hundred years after the Milan conference, there is no consensus surrounding the "ideal approach" of deaf children and, given the issues at stake as well as the shortcomings of different options, this is likely to remain so for years to come. Notwithstanding, two competing views remain to dominate the field. While implant teams may have gone along too much with inexperienced parents in their stereotype of the agony of deafness, signing deaf schools have adopted the opposite ideology in which it is assumed that the window of opportunity is by definition limited for deaf children. Parents of deaf children are caught in the middle so to say. As we argued in chapter seven, the arguments of opponents and proponents of cochlear implantation represent two poles, two values that represent the ambiguity of contemplating benefit for profoundly deaf children (Bertling 1998). This implies that to understand parents' actual decisions it is necessary to understand their real-life context. It also implies however that it is necessary to understand the ideological nature of the discourse-double that they encounter. In chapter four and five we have demonstrated how the Deaf culture discourse in particular makes a rather strong appeal to parents sense of self. On the other hand, the cochlear implant discourse caters to parents' intrinsic sense of terribleness, hope and desperation. As such both discourses may be classified as powerful actors in the field that are capable of influencing parents decisions decisively if no nuance or flexibility is provided. The most obvious example provided in this thesis was the possibility that parents refrain from implantation in favor of Deaf culture as the direct result of the virtue thesis that shapes Deaf discourse. Yet, while the rhetoric threats made in deaf ecology

may seem as more irrational and reprehensible, the silent appeal of the implant discourse should not be underestimated as we have tried to illustrate through the case of the technological imperative. The case of parents of deaf children is, as it stands today, very much ambiguous in nature as either discursive extreme represents only one end of the realities and problems parents face. To claim a non-ambiguous reality, as both discourses do to some extent, as such is to do injustice to these parents.

The contradictory and ambiguous situation of raising a deaf child is essential and will likely remain. While initially this ambiguity seems to ignite a desire for authoritarian discourses or systems "of justice and rights", which may encourage early radical choices for Deaf culture or cochlear implants, eventually many parents become weary of such solutions (Hare 1989; Rorty 1996). Some Deaf culture oriented parents eventually transferred their deaf adolescents to oral deaf schools and scolded the low-challenging environment that deaf schools provide. Some cochlear implant parents withheld mainstreaming or returned their child to a deaf school environment while many others struggled over the lack of peer interaction if the child was mainstreamed. As such parents amongst themselves seemed to realize that our discourses have failed to establish a strongly child-centred open and "critical" communication between the values represented by both of these discourses, much similar to what Hare has described in the context of conflicting moral principles (Hare 1989). Far from representing anxious and unqualified parents, these parents realize something we should take at heart, something we have failed to realize due to the "institutionalisation" of deafness and the consequent rivalry between the professional discourses of medicine and audiology on the one hand and psychology and linguistics on the other that have grown in that path.

At the time of publication of this thesis a new wave of "compromise" flourished in deaf education in the Netherlands. Resistance against cochlear implantation was also clearly on the decline. The most recent positional paper on pediatric cochlear implantation by the American National Association of the Deaf is considerably more tolerant than previous versions and Gallaudet University has opened a center for implanted children and adolescents (NAD positional statement on cochlear implantation 2001; Foreman 2001). Paraphrasing a Gallaudet University audiologist:

> "Three years ago, we weren't even discussing cochlear implants," says Debra Nussbaum, an audiologist and head of the new Gallaudet center. "But as technology has improved, people see that it doesn't have to be an either-or choice, implant or ASL," she says. "Implants are now being seen as providing additional information without trying to change the child's identity." (Foreman 2001).

The Dutch Federation of Parents of Deaf Children (FODOK) has also chosen a more positive route towards pediatric cochlear implantation (Tilanus 2001). It appears that the new axiom of "bilingualism" has succeeded in tempering the antagonism between oralism on the one hand and manualism and Deaf culturalism on the other. However, we cannot escape the impression that the decline of critique against cochlear implants is at

least in part the result of the new compromise that bilingualism represents Advocates of Sign language appear to have tempered their critique in light of the new wave of manual instruction that bilingualism has spread over deaf education in the Netherlands In this sense one may speak of a "truce in arms" This reality however, cannot automatically be taken to justify what we are doing It represents a social or political truce rather than morally justified positions per se Alden is even more critical about this new state of consensus or "manufactured consent"

> Through the use of the linguistic oppression called manufactured consent, visually impaired people [deaf people instead of Deaf people - ccw] have coerced the National Association of the Deaf into condoning the activities of the iatrolamias (cochlear implant doctors) (Alden 2001)

As such it appears that bilingualism has become the symbol of truce a political *holy grail* rather than an empirical and well-thought concept (Bertling 1998) The fact that critics have downplayed their critique does not imply that uncertainties about the benefit to deaf children remain In the case of the best-interest context, two equally valuable yet potentially conflicting sub-domains were illuminated On the one hand liberal values underscore the need to safeguard a child's future window of opportunities, yet how this is to be done depends on the political view one holds on society If one departs from society more or less fixed as it is today, different conclusions follow compared to those that depart from *potential* societies Still more complicating is the inclusion of communitarian and psychological values that are also likely shared by many Liberal values such as autonomy and self-reliance are limited by another need the need for love, friendship, community and recognition, values that may thrive better when we limit liberal values by emphasizing the value of Deaf culture In all of these issues there is a lack of empirical evidence to "silence" the dilemma, which makes it unlikely that we can reach an end-conclusion on these issues Furthermore it seems unlikely that empirical evidence ever will be able to establish this, given the fact that how we value and interpret is essential in the process There is no "empirical" threshold neither for what compromises "sufficient" happiness nor is there one which can establish what compromises "sufficient" autonomy There is no objective rule-of-thumb that can get us out of the problem of how we should weight the two against each other beyond any reasonable doubt

The fact that people have stopped to quarrel does hence not imply that the ground for quarrel has vaporized As a matter of fact we would argue that this is not the case What we need is not a new axiom that represents our desire to cease-fire and come to political compromise, but a true understanding of the legitimacy of the value of the issues at both sides of the former trench The case of deaf children is a complex one indeed, one that involves deep emotions, conflicting values and an often refractory reality that confronts us with our limited capacity to implement an ideal world A "new axiom" has no place in such a setting if we truly intend to do the best we can in the given circumstance Rather than concealing the complex nature of this reality in a new axiom

we should face up to them while avoiding paradigmatic positions as we have in the past. Though it may seem so to some, it has not been our intention to re-energize the controversy over manualism, oralism or cochlear implants. Rather we hope that this thesis will aid in stimulating thought and dialogue about the future of deaf people, deaf children in particular. Hence it seems that all we can do is outline the complexity of the issues involved as well as to at least ensure that those involved with the issues become sensitized to them. This is what we hoped to have achieved in this study. We have shown that once the political-ideological domain is eliminated neither the empirical nor the moral ramifications of the cochlear implant debate lead to a resolution to the dilemma. Indeed this moral world "is broken into pieces" which implies that we should not aim to impose "any particular conception of the good" (Murray 1997). This implies indeed that the ambiguous experience of parents correlated much closer to reality than any ideology has claimed so far. The inclination towards ideology that has been so typical of deaf education can readily be understood however. If the subject of deaf education is ambivalent in its very nature as we postulate in this thesis, if facts and rationality cannot provide a definite resolution of the dilemma's involved, this is likely to result in confusion and a consequent need for an authoritative clarity in deaf school personnel. This authority cannot be provided by empirical science however or by moral or ethical reasoning, which likely paves the road for "articles of faith" so to say.

In this thesis we hope to have shown the complexity of issues parents face when they raise their deaf child. We hope to have sensitized our readers to this, hence drawing them away from the natural inclination to seek simple solutions. This thesis, we feel, will not facilitate simpler solutions. Yet we do hope to have drawn the landscape thoroughly to those involved with the decision, such as parents, teachers, otolaryngologists and politicians. Ultimately we feel that the complexity of these issues, the conflicting claims they make and the contextuality that they assume, makes parents the most likely to succeed in reaching a sound decision. Yet we can and perhaps should assist parents in this process. By current standards, implanting every deaf child based on the "back against the wall" argument has no place and should be dismissed. Parents will likely not dismiss the argument, based on what we discussed in terms of the incongruence between the global and the individual perspective and given the metaphorical connotation of the situation that they face. At the time of the implant decision many parents will still be strongly influenced by the social prejudice on deafness, which may lean them towards implants naturally. Beauchamp and McGullough state that as such parents may indeed make poor decisions in a medical context (Beauchamp 1989b; Pritchard 1993). Upholding patient autonomy and the unabridged right to decide, like Pritchard has in the context of genetics, ignores the wider and often ambiguous issues at hand. On the other hand Pritchard has a point in that displacement of authority fully outside of the doctor-patient context, which Leuthner labels as an "expertise model", is vulnerable to abstract judgments as well as speculation and bias (Leuthner 2001). Assuming that "where there is no right answer, the parents cannot be criticized for choosing the wrong answer" seems overly relativistic (Buchanan 1989). From the fact that there is no right answer in the

sense of a single, uniquely correct solution, it does not follow that one answer is as good as the next. Yet to do so does not entail that we institute yet another decentralized expert-panel, but that we engage in direct dialogue with parents so to safeguard the merits of the decision-making process they go through (Buchanan 1989). Listening to and recognizing their worries, providing the necessary data where needed, reflect with them on the dual nature of the decisions they face without resorting to the kind of ideology that typifies both Deaf culturalism as well as cochlear implantation. That means making sure that they obtain the necessary information and making sure that they are aware of the realistic feasibility of the project. It seems to us that, given the complex and multi-disciplinary issues involved, this could best be realized by a positive, eclectic and pragmatic cooperation between deaf schools and implant teams.

SUMMARY IN ENGLISH & DUTCH

SUMMARY

Profound sensorineural hearing loss is a rare condition that affects about 0.2% of the population in Western nations. Hearing loss of this severity has some rather weighty implications, most significantly its devastating effect on access to spoken language. Profoundly deafened people are generally severely limited in their ability to discern spoken language cues, even if assisted by optimal conventional hearing aids. As a result, even the most basic conversation can become rather unattainable, which yields severe social implications. If profound hearing loss originates before spoken language is acquired, a critical impediment of spoken language acquisition is almost inevitable.

For many centuries the origin of spoken language impediment of profoundly pre-lingual deaf people was poorly understood. Deaf "mutes" were believed to lack the cognitive skills to develop spoken language. As such, their state was considered irremediable, which made their cultural representation more or less similar to other mentally disabled citizens. In the 17th century the representation of deaf mutes changed to our current understanding. Since then deaf education has become institutionalized and much effort has been realized to cater to the specific "problems" that pre-lingual deaf children face. Since then, two rather distinct verbalizations of how we ought exactly to perceive of the "problems" that deaf children face have also surfaced. One view, labeled "manualism" has placed manually codes language center stage. In a manually coded language, profoundly deaf individuals do not experience the limitations of their handicap and can hence access language and knowledge speedily and effortlessly. Another view, labeled "oralism" has stressed the importance of socio-cultural participation and as such has underlined the need for spoken language skills. Advocates of oralism have relentlessly sought strategies to improve deaf children's severely inhibited access to spoken language cues, through sound amplification and rigorous speech and lip-reading training. This latter view dominated deaf education from the end of the 19th century up to the 1970s. Driven by poor outcomes and growing evidence of the benefits of sign language education, many Western deaf schools shifted to sign-based instruction in the last decades of the 20th century.

The application of cochlear implantation in pre-lingual deaf children has stirred great controversy and has divided opinion amongst many of those involved with these children. The controversy has produced an array of arguments in a large assortment of media, ranging from professional otolaryngological, ethical and deaf education journals, to the popular media. The adult Deaf community, who perceive themselves as a proud linguistic minority, has expressed indignation over the suggestion that young deaf children benefit from enhanced sound awareness and perceive of cochlear implantation as an assault on their dignity as well as their political case. Professionals in the fields of linguistics, deaf education and psychology have also responded skeptical. They have warned that the introduction of cochlear implants may lead to a resurfacing of "oralism", an educational paradigm that dominated the field of deaf education from the end of the

19th century up to the mid 1970s. This paradigm roughly represents the idea that oral language skills are overriding in terms of a deaf child's best interest, regardless of the odds of success, in spite of potential psychosocial liabilities and even if it entails significant sacrifices in terms of a child's access to sign language. Indeed, critics have suggested that psychosocial liabilities likely disfavor cochlear implantation over sign language and have argued that the odds of success are liable to be low. Led by their drive to undo deafness, parents have been depicted as unqualified judges of the appropriateness of cochlear implantation for an individual deaf child. Finally, the most radical opponents of cochlear implantation have rendered the implant technology as unethical based on cultural or political-philosophical arguments, claiming that even a "perfect" cure for deafness ought to be perceived as a moral straying.

This study aims to broaden en deepen our understanding of the moral landscape in which cochlear implantation is embedded. Parents of deaf children are a rich and much ignored source of information in this context. On the one hand, they have lived-through deafness first hand and as such have much to tell about their experiences. They can enhance our understanding of the emotions that having a deaf child inflicts, the dilemma's they are faced with, the information they receive and the values and paradigms that characterize deaf education today. On the other hand, parents themselves have been a rather central factor in the deaf educational debate in general, and the cochlear implant debate specifically. By proxy, parents can decide where to enroll their child, which language of instruction is paramount and, since the late 1980s, whether to proceed with cochlear implantation or not. While much has been claimed about how parents reach their decisions vis-à-vis their deaf child, this has been based on casuistry mostly.

In chapter one we present a birdseye view of deaf educational history. For this purpose we have identified five separate periods, from the period before 1750 to our present day. A crucial change took place around the 16th century when deafness was recognized as a separate cause of language impediment, much different to cognitive retardation. This awareness gave birth to deaf education and the establishment of the first deaf schools during the 18th century. While from the start, educators quarreled about the instructional method of choice the 1880 Milan conference strongly pitched deaf education towards oral instruction as opposed to sign language. This situation was to continue up to the 1960s when sign language found its way into the limelight once again. Triggered by disappointing results of oral education in terms of spoken language proficiency, cognitive development, educational and societal achievement and based on landmark linguistic and psychological research, sign language slowly gained influence throughout the 1960s and 1970s and became the leading educational paradigm at many deaf schools in the final two decades of the 20th century. Today sign language is the language of choice for many, though certainly not all, profoundly deaf individuals. Not only do many deaf people communicate through sign, they often socialize amongst peers as well. This social-linguistic unit is often referred to as Deaf culture: at least one-third of

all profoundly deaf people identity with Deaf culture almost exclusively. It is in this cultural climate that pediatric cochlear implantation was introduced in the mid 1980s. Though initial research started as early as the 1950s, it took many years before the device was introduced in the clinical trial phase. Cochlear implants aim to provide auditory cues to profoundly deaf individuals by offering electric sound signals directly to the inner ear, thereby enhancing access to spoken language. Technology assessment trials have indeed shown that implanted children improve significantly in identifying words in a closed-set environment, while many also advance in an open-set setting. Speech intelligibility also appears to improve. In terms of development of spoken language, implanted children appear to excel beyond their projected learning curve and a relatively large number of implanted children attend mainstream education. Though it is difficult to draw general conclusions from the reported data, many assume that cochlear implants are a viable resource for profoundly deaf children. Today cochlear implantation is available in many countries and over 20000 children have received an implant worldwide. In spite of the rise of cochlear implantation, many remain skeptic. Skeptics worry that cochlear implantation will revive the appealing yet unproven dream of oralism, and fears that many deaf children will be victimized as a result. Critics argue that trials have been weakly designed and incompletely reported on. It is moreover feared that far fewer implanted children will actually succeed in spoken language terms than the data suggests. As such critics fear that cochlear implants will drive young deaf children away from sign language and Deaf culture while ultimately failing to yield the kind of success needed to actually succeed in hearing society. While positive reports of cochlear implantation tempered critique in the final years of the 20th century, the controversy continues in some circles.

In chapter two we discuss the ethical and methodological premises of this thesis. We provide a very brief history of medical ethics from the 1960s to our present day. For many years the dominant mode of medical ethics materialized as "rule-based" or "principle based". This roughly implies that medical dilemma's are analyzed conforming a closed set of moral laws. Critics have argued that this form of ethics has some shortcomings, most importantly that it limits itself to the "facts" of a case and is rather blind to the detail of the context in which the case occurs. One way of replenishing this potential blind spot, is to explicitly include the context in an ethical analysis. As such it has been argued that we ought to reach out to the people who are actually faced with a specific moral dilemma: we should study their story, try to understand their values, try to understand the nature of their dilemma and elicit how they go about finding a way out. Narrative ethics is one ethical school that tries to address these issues. It should not so much be perceived as a replacement but rather as a supplement to conventional rule-based ethics. This study is guided by the paradigm of narrative ethics. Our concern in this study is not so much with "what" parents do, but "why" they do what they do. This has direct consequences for the methodology of our study. This study is based on empirical material that was gathered through semi-structured, explorative and in-depth interviews with parents of deaf children. As such our methodological approach can be classified as

"qualitative" as opposed to the more "quantitative" design of closed-set questionnaires We interviewed 23 parents of profoundly deaf children in the age group 3-15 years Sixteen respondents were the parent of a deaf child with a cochlear implant, while seven parents did not choose for cochlear implantation

In chapter three, we describe parents' experiences prior to the diagnosis and during the period directly thereafter This period is rather crucial for several reasons perhaps most importantly it provides important clues about parents' early coping process One crucial finding was that parents were all deeply shocked by the diagnosis, independently of the cause of deafness and independently of case-control status Even though some parents experienced the diagnosis as a "relief" in terms of lifting the uncertainties that characterized the period prior to the diagnosis, the general tenor was one of cataclysmic sadness Their agony materialized as rather diffuse however, even though some specific concerns did arise, meaning that parents were typically unable to explain to us *why* they were so upset by the diagnosis We hypothesize that this very global sense of "tragedy" originates in our cultural stereotype of deafness, a stereotype that portrays deafness as an inexorable source of sadness that precludes any joy of life In spite of the intense shock over the diagnosis, we found that parents soon succeeded to reset themselves Hands-on experience with the deaf child was paramount here The emotional and relational prosperity of the child was a strong antidote to the catastrophic image that parents held before The vast uncertainties of the future were cast aside as parents focused on the progress that their child did make, albeit in small steps

In chapter four, we describe parents' experience after the diagnosis has settled for some time This period coincides with some crucial decisions that parents face, in terms of language and education It has been suggested that some parents never come to "accept" their deaf child This thesis of *non-acceptance* may be captured by psychological coping theory or may alternatively refer to the concept of "attitude" Both avenues have been explored in deaf literature, albeit rather unrefined while several studies assume that specific decisions are symptomatic of non-acceptance, few studies have actually scrutinized parents' position from a process vantage point It has been commonly assumed that parents will be focused on eliminating deafness rather thoughtlessly as a result of these internal processes Since we feel that focusing on outcome alone is a deficient working model in this context, we attempt to deductively define phenomena that correlate with non-acceptance and to probe for their occurrence in our empirical material We focus on expectations that parents held and hold of their deaf child as well as their convictions about the state of being deaf We also probed for emotions of disappointment, resentment, shame, pity and sorrow Finally we explored potential behavioral reciprocals such as rejection, evading behavior and the inability to form an authentic relationship with the deaf child In terms of expectations we found that parents were modest in their verbalizations Parents ignored the larger problems that await a deaf child in the future, and as such were hesitant to talk about concrete expectations Rather their expectations were set in a shorter time frame and were mostly

socio-relational in character. While we did find that deafness induces radical change in the family, a change that was not always welcomed warmheartedly, parents were certainly not disappointed and did not experience feelings of resentment. In terms of shame and evading behavior we did find some feelings of discomfort over the use of sign language in public. Though we cannot exclude the possibility that this finding underscores the thesis of attitudinal non-acceptance, we feel that other explanations may also apply. Parents did not perceive their deaf child as pitiful, yet continuously encountered this stereotype in the gaze of others. Parents experienced this as an assault on the individuality of their child and on the loving relationship they held with him or her. Nonetheless parents did appear to experience grievance, though this was not an encompassing and intrusive experience as it was around the time of diagnosis. Moreover, contrary to parents' earliest emotional state, grievance was mostly specific in this phase: it was not a global form of grievance that relates to a prejudiced view on deafness, but was associated with specific limitations that deafness instates. Finally, grievance over deafness did not seem to trespass into grievance or pity *over* the deaf child: parents seemed to separate the "what" of deafness from the "who" of their existential-relational child. As such parents could grieve over their child's limited ability to learn speech without allowing this to intrude into their view of and their relationship with their child. Our findings about parents' coping process or "attitude" correlate well with behavioral reciprocals in terms of language and educational choices. We found that parents were mostly well prepared and ready to decide. Though the information that parents received was often biased and incomplete, most parents chose sign language as their child's primary language. The primary motives for doing so were pragmatic and emotional-relational in nature: to provide their child a communicative means of high quality early on, to facilitate the parent-child relationship, to optimize the child's affective well-being and to instate an environment that parents perceived as most appropriate for young children. Some parents alluded to non-negotiable motives however and referred to deafness as an identity or cultural determining trait, a discourse that we label Deaf Culture Identity (DC-ID). Most of these parents had enrolled their child at a signing school for the deaf. Still, school choice in itself was largely determined pragmatically by geographic factors.

In chapter five, we describe parents' experiences as their child reaches school going age. One crucial factor on which we will focus in this chapter is the role of deaf school personnel and peers, a social environment that we label "Deaf ecology". Given the asymmetry between parents and school personnel, given the fact that we found that parents whose child attended a signing school for the deaf were more likely to argue in terms of DC-ID, given the fact that DC-ID represents a rather abstract discourse, the fact that time will likely induce increased knowledge and wisdom and given the fact that growing children will themselves "claim" a place in parents' deliberations, it becomes interesting to study if and how parents' views change over time and how interaction with Deaf ecology fits into this change. It appears that schools for the deaf – most evidently those who fame themselves for their sign language axiom - uphold the arguments

encapsulated by DC-ID as time progresses. A secluded environment was pervasively depicted as the most suitable for deaf children. Socio-emotional arguments were paramount in this context. Deaf children were depicted as "special" and "vulnerable" children who need to be protected from the outside world and who ought not be challenged too much. We also found that the advocacy of such a protective environment was founded on arguments of "acceptance": parents were told that any dissent from the deaf school protocol was to be perceived as proof of non-acceptance, of "bad" parenthood and "intolerance". The legitimization was pragmatic at times, as deaf school personnel alluded to the tragic experiences of deaf adults. Yet ultimately this argument appears to be founded on the essentializing thesis that deaf children "natively belong" to Deaf culture and have a "right" to be culturalized in this environment. Parents who considered dissent from the deaf school protocol were repudiated on moral grounds and were socially isolated and reprimanded. Parents on the other hand, clearly changed in their views as time progressed. When we focused on parents of older children (at least 8 years of age) we found that parents generally abandoned their exclusive socio-emotional perspective on their child's well-being: parents became increasingly focused on their child's needs in the future and abandoned the encompassing perspective of DC-ID and developed a strongly child-centered attitude instead. Parents did not only feel that pervasively depicting deaf children as "vulnerable" is stigmatizing and harmful to their future needs, they also felt – based on their child's specific characteristics - that it was rather inappropriate in the context of their individual child. As such parents explored more challenging avenues for their deaf youngster, which included the challenge of learning spoken language, educational mainstreaming and exposure to hearing society. In doing so they constantly monitored their child and were sensitive to the chance of failure, which sometimes resulted in a reversal of challenges if the child appeared not adept to deal. Yet deaf schools repudiated such pragmatic initiatives and confronted parents with DC-ID arguments. Parents responded to this by debunking the essentialist claims of DC-ID. Parents revolted against the "traditional imprisonment" that DC-ID symbolizes in their view, rebelled against the authority claim of deaf ecology and disengaged the link between the DC-ID prescriptions and their moral status as parents. As such parents emerged as rather pragmatic "self-willed" guardians of their deaf child's best-interest.

In chapter six, we focus on cochlear implantation specifically. For most parents the first news about implants became available quite some time after the diagnosis was established. When parents visited the implant team, they received rather modest information in terms of what they could expect. Implant teams appeared to focus on the possibility of enhancing hearing and steered clear of promises in terms of spoken language proficiency. The media were much more speculative in their reporting however, as many early report were not inhibited in their enthusiasm and seemed to mix-up positive self-reported results in post-lingually deaf people with the case of pre-lingual children. In spite of the modest information by implant teams, many parents declared to have been "sold" on cochlear implantation rather instantly, though we also found that this enthusiasm did not lead to a lack of healthy skepticism. Deaf ecology was generally

critical about cochlear implantation, though this was not the case for personnel of one "oral" school for the deaf. The range of arguments against cochlear implants was highly synchronous with DC-ID critique that we discussed in the previous chapters: cochlear implantation has even been depicted as "identity-surgery". Specific about cochlear implant critique was skepticism about its efficacy. When exploring why parents chose for cochlear implantation, many parents initially evaded the topic of spoken language and narrated about increased sound awareness instead. On further inquiry however, most parents acknowledged that sound awareness alone was an insufficient reason to option for implantation. Parents clearly "hoped" that cochlear implantation would increase the likelihood that their child would master some spoken language skills, which in turn was reasoned to cater to their child's future opportunities. Most parents were well aware of the chance that their hopes would not materialize, and as such kept the door to Deaf culture open. It appeared that many of our controls did not actually choose "against" cochlear implantation, since the device was unavailable to their child. Nonetheless it did appear that controls were somewhat more skeptic about the efficacy of cochlear implantation and worried more over potential liabilities. A few controls upheld DC-ID arguments in their response to implant technology, though we did not find these arguments to be paramount. Most controls acknowledged that they would option for a cochlear implant *if* implant technology were perfect. Implant surgery was generally not experienced as particularly burdensome by parents. The revalidation period was initially characterized by carefully adjusting the child to the new device so to avoid aversion, which parents feared. Early implant results were generally reserved. It took quite some time before results materialized and initial results were mostly limited to modest advances in sound awareness. Nonetheless parents were inclined to respond blissfully. As implant results improved, some parents started to consider a transfer to a mainstream educational setting to facilitate the process. Focusing on the narratives by parents of the most experienced (over 18 months of experience) implanted children, we found that implant results continue to increase over a span of many years. Eventually most of these children became proficient in spoken language, even though the degree of success varied. Gain in spoken language proficiency appeared to induce a tapering of sign language and an increase in educational mainstreaming. Parents were generally content with long-term implant results, even though they continued to "hope" for better results and continued to perceive of the future as rather uncertain. Parents whose child attended a signing school for the deaf were generally more reserved about the odds of success.

In chapter seven we define the appropriate moral space to analyze pediatric cochlear implantation from a moral or ethical perspective. Most crucially, we address the encompassing nature of the DC-ID argument. Even though most parents discarded the DC-ID arguments, we cannot simply adopt this position. If the DC-ID arguments are judged to be legitimate, a pragmatic appraisal of cochlear implantation becomes rather inappropriate. The DC-ID arguments hinges on the concept of "acceptance". Yet this is a multi-layered concept indeed. On the one hand "acceptance" alludes to psychological coping theory. Central to this paradigm is that certain events may lead to decisions that

are "unconstructive" to the subject in case In the case of parents of a disabled child, pathological coping may imply that decisions are taken that are "unconstructive" vis-a-vis the child's best-interest We feel that such a view does not apply to our respondents A more complicated matter is the view on acceptance that alludes to parents' moral attitude as "unconditionally" loving parents Deaf ecology clearly prescribed which "conditions" matter in this context and as such defines the "rules" of the acceptance claim, and as such acts as a moral agent This claim placed a heavy burden on parents It appeared that most parents eventually debunked the premises of this claim, by freeing the child from the encompassing scripts of deafness Parents also questioned if the prescriptions of DC-ID were to be perceived as pragmatically inevitable Indeed it seems open to discussion if challenge and exposure to hearing society *necessarily* lead to "injured" identities as some have suggested We feel that empirical evidence fails to establish this premise beyond a reasonable doubt The strongest assault against cochlear implants is shaped by the foundational Deaf culture argument, which draws on an association with the case of ethnic or racial minorities Lane has verbalized this position most expressively in his rejection of the hypothetical case of the "perfect" cochlear implant Lane rejects such a hypothetical case, based on the same moral arguments that structure assaults on ethnic identities We explore this comparison at length to conclude that the case of racial identities does not apply to the case of young deaf children, at least not uncomplicatedly What does stand, it the *strategic advantage* of a foundational Deaf culture discourse in countering the threat of unrestrained enthusiasm over the prospects of cochlear implantation - in light of what critics assume are narrow results As such we hypothetically conclude that the foundational Deaf culture argument is a political argument, which is intended to fulfill this strategic role primarily In an encompassing form, it risks turning into a coercive self-fulfilling prophecy, which can harm rather than benefit the interests of deaf children As such, we feel that the foundational Deaf culture argument provides an inadequate moral space to analyze the case of cochlear implantation, and that we should proceed to scrutinize the issue beyond this "moral deterrent" from a best-interest perspective To do so requires that we define the concept of best-interest in more detail This question draws us to the controversial field of child advocacy Liberal child advocacy verbalizes a child's best-interest in terms of the liberty to determine ones own life-script, which requires that certain basic opportunities are realized While extreme liberals may argue that parents ought to "optimize" their child's opportunity to identify with as many life prospects thinkable, others have stressed that such a demand is excessive and ignores the interrelatedness of parent and child Rather, it is postulated that parents ought to provide in a "reasonable" range of life prospects that is life prospects which a child can "reasonably" be expected to claim and which parents can "reasonably" be expected to accept The case of Wisconsin versus the Amish Yoder family illustrates that, even in the case of non-disabled children, such a paradigm is not uncomplicated In the case of disability, the problems become only larger what should we consider "reasonable" life prospects in the case of deaf children? Critics have argued that our current Deaf adult population represents the only reasonable life prospect for deaf children We feel that this argument is flawed, and as such is an inadequate motive

to a priori withhold broader life prospects for deaf children. Of more fundamental significance is the questionable suitability of the liberal child advocacy paradigm to the case of disabled children. This is most effectively illustrated in the case of profound mental retardation. If we consider the autonomy to choose ones own life path as the alpha and omega of a best-interest analysis, we clearly encounter rather severe problems in this latter case. Under some circumstances, curtailing this right may at the end of the day "benefit" such a person much better. The importance of care and socio-emotional security is rather self-evident in the case of people with a profound retardation. In spite of this truism, we do risk that this "self-evidence" trespasses into the blind paternalism of an encompassing care-ideology. This treat becomes only larger in the case of disabilities with a far larger scope of possibilities, such as deaf children. As such we feel that it is undesirable that we reduce our moral space to care-ideology in contemplating a deaf child's best-interest, as some deaf schools seem to have preferred. Still, to ignore the limitations that deaf children have and to ignore the values of care and socio-emotional security altogether is an equally unreasonable option. As such, an analysis of deaf children's best-interest should always be an eclectic and balancing enterprise that seeks to reasonably integrate "liberal" values such as autonomy and "communitarian" values such as care and socio-emotional security. We feel that our material shows that, in terms of a general parenting "attitude", parents succeeded in this rather accomplishedly.

In chapter eight we will present our final pragmatic and eclectic best-interest oriented analysis of the cochlear implant debate. To do so requires that we meticulously look at the specific merits of cochlear implantation as well as the alternative of Deaf culturalism in terms of a deaf child's best-interest, and that we do so beyond the rhetoric that has characterized much of the debate so far. We assume that both proponents of cochlear implantation as well as advocates of Deaf culturalism reason along the lines of best-interest, and that both must thus depart from a specific "benefit-model" in which pro's and con's of the two options are arranged. Such benefit-models likely feed on empirical information, but they are equally likely to be structured by rhetoric and perhaps even prejudice. We attempt to illuminate these benefit-models and comment on them. A crucial issue that we address is the broad critique that has been raised over the so-called "classic" medical paradigm. One of the main flaws of this paradigm is that it is inclined to equate measurable physiological "effect" to "benefit". Through the powerful case of life-saving procedures we draw the shape of this critique, and side with it in concluding that such a view can lead to a rather undesirable form of self-justifying rhetoric, which we label as a "no-lose philosophy". We argue that the utility of medical procedures should be looked at beyond such a silencing paradigm. We argue for a more comprehensive benefit-model in which "benefit" is defined more broadly than physiological effect, and make a case for including the fate of treatment failures in such an appraisal. We continue to apply this view to the case of pediatric cochlear implantation. We declare a no-lose philosophy categorically unfit to this case, given the fact that the non-treatment alternative is not nearly as nihilistic as in the case of life-saving procedures. Moreover, we assert that "not hearing" in itself is a "minor" problem

in the context of the profound difficulties that deaf people encounter in life. As such we oppose the idea that "any" gain in terms of "effect" legitimizes cochlear implantation, and that we as such must proceed to analyze benefit and disbenefit more closely. To do so requires that we define the benefit-model of implant teams in more detail than gains on the decibel scale. We postulate that spoken language acquisition and, ultimately, enhanced future opportunities are the benefits that cochlear implantation assumes. We continue to analyze the case of cochlear implantation by separately discussing three central positions: the case of successfully treated children, the case of treatment failures and the case of the Deaf culture alternative. We conclude that cochlear implantation can make a valuable contribution to a deaf child's best-interest, yet warn that the convincingness of the treatment depends on several conditions. Perhaps most importantly, non-use should be considered a treatment failure and as such contributes negatively to the net utility of the treatment. Cochlear implant failures will very likely occur, and the likelihood may be larger than hoped. Implant teams should make a strong effort to limit the likelihood of this occurrence by vigorously looking for confounding factors. Implant teams should also make a vigorous effort to limit the magnitude of failure, by carefully monitoring implanted children over the course of many years, and by manifesting an eclectic preparedness to change-course in time. To do so requires that axioms are abandoned and demands a close cooperation with schools for the deaf. Conversely, deaf schools also need to abandon their ideological stance, if such an eclectic cooperation is to be realized and if they take their task of facilitating a deaf child's best-interest seriously.

The case of deaf children is a complex and ambivalent case by its very nature. For over two hundred years, deaf education has responded to this ambivalence by resorting to one of two ideological positions. Today we face a unique challenge that we should harvest rather than dodge. Sign language has been introduced in most schools for the deaf and much effort is put into improving education for deaf children. At the same time we have a technology available that realistically allows at least some deaf children access to spoken language, which can broaden their opportunity interests. The eclectic and child-centered attitude of parents of deaf children are a beacon on the horizon, the harbinger of a future in which paradigmatic differences can finally be lifted. We are utterly convinced that this is the right thing to do, if we take our social responsibility towards deaf children seriously.

SAMENVATTING

Totale doofheid is een relatief zeldzame aandoening die ongeveer 0.2% van de bevolking van Westerse landen treft. Totale doofheid heeft ernstige consequenties, met name voor de toegankelijkheid tot de gesproken taal. Dove mensen ondervinden doorgaans grote moeite met het kunnen onderscheiden van klanken, zelfs bij gebruik van de meest geavanceerde hoortoestellen, waardoor het voeren van zelfs elementaire gesprekken vrijwel onmogelijk is. Het spreekt voor zich dat dit grote sociaal-maatschappelijke consequenties heeft. Wanneer doofheid vóór het derde levensjaar ontstaat (wij spreken dan van "pre-linguale" doofheid), is de ontwikkeling van gesproken taal bovendien uiterst onzeker: slechts een kleine minderheid van alle pre-linguaal doven slaagt erin de gesproken taal zodanig meester te worden dat deze in het sociaal-maatschappelijk verkeer inzetbaar is.

Gedurende vele eeuwen was de oorzaak van het uitblijven van spraak bij pre-linguaal doven volstrekt onbegrepen. Lang heeft de idee bestaan dat "doof stommen" niet over de benodigde cognitieve capaciteit beschikten om zich de gesproken taal eigen te maken. Aldus meende men dat het zinloos was hiertoe pogingen te ondernemen. Pas in de 17e eeuw kwam hierin verandering, en werd onderkend dat specifiek het ontbreken van auditieve informatie verantwoordelijk was voor het uitblijven van gesproken taal. Sinds die tijd is het onderwijs aan doven in een stroomversnelling gekomen. Met het op gang komen van het specifieke dovenonderwijs, ontstond eveneens een schisma dat tot in onze tijd zou voortduren. "Manualisten" meenden dat het dovenonderwijs zich primair op gebarentaal zou moeten richten, omdat gebaren voor doven makkelijk toegankelijk zijn en aldus het meest efficiënte medium zijn om kennis te vergaren. "Oralisten" daarentegen, meenden dat de aandacht zich primair zou moeten richten op het aanleren van gesproken taal, daar deze taal een voorwaarde is om aan de samenleving te kunnen participeren. Vanaf het einde van de 19e eeuw tot aan de jaren '70 was het oralisme dominant binnen het dovenonderwijs. Mede naar aanleiding van tegenvallende resultaten van de orale methode en het groeiend bewijs van de positieve aspecten van gebarentaal, zijn veel dovenscholen gedurende de laatste decennia van de 20e eeuw overgegaan tot het invoeren van gebarentaal in hun onderwijssysteem.

Medio jaren tachtig kwam cochleaire implantatie beschikbaar als medische behandeling voor pre-linguaal dove kinderen. Het primaire doel van cochleaire implantatie is de verbetering van de toegang tot auditieve informatie, om aldus de mogelijkheden tot het ontwikkelen van gesproken taal te vergroten. Aldus raakte cochleaire implantatie betrokken in de eeuwen lange verhitte controverse tussen manualisten en oralisten. De doelstelling van deze studie is ons begrip van het morele debat rondom cochleaire implantatie te verbreden en verdiepen. In dezen beschouwen wij ouders van dove kinderen als een belangrijke informatiebron. Enerzijds kunnen zij als "ervaringsdeskundigen" worden opgevat: meer dan welke instantie ook, hebben zij doofheid van dichtbij ervaren en moeten doorleven. Als zodanig kunnen zij ons inzicht

vergroten ten aanzien van de emoties die het hebben van een doof kind teweeg brengt, de dilemma's waar ouders voor gesteld worden, de informatie die ontvangen wordt en de normen en waarden die het dovenonderwijs kenmerken. Anderzijds staan ouders zelf centraal in het debat dat binnen het dovenonderwijs gevoerd wordt, wellicht nog sterker in het debat rondom cochleaire implantatie. Het zijn immers de ouders die uiteindelijk beslissen over taal en onderwijs kwesties, alsook over het al of niet aanmelden van hun kind voor cochleaire implantatie. Hoewel er veel beweerd is over de beweegredenen van ouders, beperken deze beweringen zich doorgaans tot casuïstiek.

In hoofdstuk 1 van dit proefschrift wordt een kort overzicht van de tumultueuze geschiedenis van het dovenonderwijs gepresenteerd. De ontdekking dat doofheid, en niet cognitieve retardatie, de oorzaak was van het uitblijven van gesproken taal is een cruciaal moment in de dovengeschiedenis. Als gevolg van deze ontdekking werd het specifieke dovenonderwijs geboren en werden in de 18e eeuw de eerste dovenscholen gesticht. Vrijwel onmiddellijk ontstond er een paradigmatisch debat tussen manualisten en oralisten, een debat dat echter in 1880 in Milaan in het voordeel van het oralisme werd beslecht. De orale onderwijs methode bleef tot in de jaren '60 van de vorige eeuw dominant. Naar aanleiding van slechte resultaten van de orale methode in termen van het ontwikkelen van gesproken taal, cognitieve ontwikkeling, onderwijs prestaties en maatschappelijk functioneren en op basis van baanbrekend onderzoek naar gebarentaal en het psycho-emotioneel functioneren van doven, groeide de invloed van gebarentaal in het dovenonderwijs uit tot de dominante positie die zij vandaag de dag inneemt. Heden ten dage is gebarentaal voor veel, doch zeker niet alle, pre-linguaal dove volwassenen het primaire communicatie medium. Behalve de voorkeur voor gebarentaal is er een tweede element dat veel dove volwassenen kenmerkt: hun voorkeur voor socialisatie met andere doven. Tenminste eenderde van alle dove volwassenen heeft een voorkeur voor deze sociaal-linguïstische constellatie, die ook wel "Dovencultuur" wordt genoemd. De introductie van cochleaire implantatie, medio jaren '80, moet tegen deze sociaal-historische achtergrond worden bezien. Hoewel het onderzoek naar cochleaire implantatie reeds in de jaren '50 begon, duurde het nog vele jaren voordat de techniek aan klinisch onderzoek werd onderworpen. Het doel van cochleaire implantatie is het vergroten van auditieve input - en daarmee het verbeteren van de toegang tot gesproken taal - door een elektrisch geluid-signaal direct aan het binnenoor aan te bieden. Onderzoek heeft aangetoond dat kinderen met een cochleair implantaat inderdaad beter in staat zijn om woorden te herkennen, en dat de verstaanbaarheid van hun spraak toeneemt. Voor wat betreft het ontwikkelen van gesproken taal, zijn er aanwijzingen dat geïmplanteerde kinderen de verwachte ontwikkelingscurve zonder implant overstijgen. Een relatief groot deel van geïmplanteerde kinderen zit thans in het reguliere onderwijs. Hoewel het moeilijk is om op basis van het huidige onderzoek algemene conclusies te trekken, menen velen dat cochleaire implantatie een waardevolle behandeling is voor dove kinderen. Thans hebben wereldwijd meer dan 20.000 pre-linguaal dove kinderen een cochleair implantaat ontvangen.

De introductie van cochleaire implantatie gaf vrijwel onmiddellijk aanleiding tot een diepe controverse onder allen die op de een of andere manier betrokken zijn met het welzijn van dove kinderen. De controverse gaf aanleiding tot een uitvoerige discussie die in verschillende media werd gevoerd, en waaraan velen een bijdrage leverden. Vooral volwassen Doven, die zichzelf als een trotse minderheid zien, waren verontwaardigd over de suggestie dat jonge dove kinderen werkelijk baat zouden hebben bij een verbeterde geluidsperceptie, die door implantatie teams in het vooruitzicht werd gesteld. Bovendien beschouwen zij cochleaire implantatie als een aanval op hun met veel moeite veroverde waardigheid en de belangen van hun politieke emancipatie strijd. Linguïsten, psychologen en leerkrachten uit het doven onderwijs reageerden eveneens met scepsis. Critici menen dat de psycho-emotionele consequenties van cochleaire implantatie aanzienlijk zullen zijn en benadrukken de bescheiden en soms slecht gefundeerde successen die door implantatie teams zijn gerapporteerd. Cochleaire implantatie zou bovendien, door haar appèl aan de waarde van de gesproken taal, tot een heropleving van het oralisme kunnen leiden, en aldus de nog maar net op gang gekomen strijd voor gebarentaal teniet kunnen doen. De meest radicale tegenstanders van cochleaire implantatie beargumenteren dat de techniek, zelfs al zou zij technisch perfect zijn, op politiek-filosofische gronden moreel verworpen zou moeten worden.

In hoofdstuk 2 worden de ethische en methodologische premissen van dit onderzoek besproken. Als zodanig presenteren wij een kort historisch overzicht van de opkomst van de medische ethiek vanaf de jaren '60. Lange tijd is het dominante model binnen de medische ethiek gebaseerd geweest op enkele leidende principes, zoals "autonomie", "weldoen" en "rechtvaardigheid". Dit betekent dat ervan uit wordt gegaan dat medische dilemma's zich laten schikken naar een tamelijk abstract analyse model. Critici menen dat deze aanname aanvechtbaar is, en dat door de beperking tot de "feiten" van een ethische kwestie waardevolle contextuele informatie verloren gaat. Critici menen dat ethici zich expliciet zouden moeten bekommeren om de lokaliteit van een moreel dilemma en aldus zouden moeten proberen de lokale context te beschrijven en te verhelderen. Narratieve ethiek is tegen deze achtergrond één mogelijk ethisch alternatief, of beter gezegd "aanvulling", op het klassieke ethische model. In dit onderzoek laten wij ons leiden door de aanvulling en verrijking die een narratieve ethische benadering biedt. Onze vraag richt zich dan ook niet primair op "wat" ouders van dove kinderen doen, maar "waarom" zij tot bepaalde beslissingen komen. Deze positie heeft directe consequenties voor de methodologische aanpak van het onderzoek. Het in deze studie gehanteerde empirische onderzoekinstrument bestaat uit semi-gestructureerde, exploratieve diepte-interviews met ouders van dove kinderen. Als zodanig kan dit onderzoek als "kwalitatief" worden aangemerkt. Wij interviewden 23 ouders van dove kinderen in de leeftijd van 3-15 jaar, waarvan 16 voor een cochleair implant gekozen hadden.

In hoofdstuk 3 beschrijven wij de ervaringen van ouders vòòr en direct rondom the diagnose. Deze periode is van belang om ons een beeld te vormen over het vroege

"coping" proces dat ouders doormaken. Vrijwel alle ouders gaven te kennen diep geschokt te zijn geweest door de diagnose. Ondanks de bevinding dat sommige ouders de diagnose als een "opluchting" ervoeren, in de zin dat deze een eind bracht aan de onzekerheid die de periode voorafgaande aan de diagnose kenmerkte, spraken de meeste ouders van een bijna apocalyptisch te noemen bedroefdheid. Bij navraag bleek dit leed echter opvallend aspecifiek te zijn. Hoewel sommige ouders refereerden aan specifieke zorgen en angstbeelden, konden de meeste ouders nauwelijks inhoud geven aan het leed wat hen ten tijde van de diagnose trof. Op grond hiervan wordt in dit onderzoek geconcludeerd dat dit globale en aspecifieke leed waarschijnlijk gecorreleerd is aan de culturele karikatuur van doofheid, waarin doof zijn wordt afgebeeld als een "vreselijke gebeurtenis" die elke vorm van levensvreugde uitsluit. Ondanks dit aanzienlijk leed, bleek dat de meeste ouders zich vrij snel herstelden. Directe ervaring met het dove kind was hierbij de belangrijkste stimulans voor een veranderend perspectief. Het emotionele welzijn van het dove kind en de kwalitatief bevredigende relatie tussen ouders en kind leerde ouders dat de catastrofale karikatuur van doofheid ontoepasselijk is. De enorme onzekerheden ten aanzien van de toekomst werden door ouders min of meer ter zijde geschoven: ouders oriënteerden zich primair op de kleine vorderingen die hun kind in het hier en nu realiseerde.

In hoofdstuk 4 beschrijven wij de ervaring van ouders in de periode kort na de diagnose. Deze periode is van belang, gezien ze samenvalt met enkele cruciale beslismomenten ten aanzien van taal en onderwijs. In de literatuur wordt gesuggereerd dat ouders van een doof kind het gehandicapt zijn van hun kind nooit "accepteren". Deze non-acceptatie these kan gezien worden als een correlaat van de psychologische "coping" theorie, dan wel als een verwijzing naar het morele concept "attitude": beiden zijn terug te vinden in de doven literatuur, hoewel ze conceptueel en procesmatig zelden goed worden onderbouwd. Een populaire these is dat non-accepterende ouders gedachteloos streven naar het opheffen van de handicap. Echter, het eenzijdig benaderen van dit vraagstuk op grond van de concrete beslissingen die door ouders genomen worden is onvoldoende en opent de weg voor ongefundeerd moralisme. Als zodanig hebben wij deductief gezocht naar minder concrete fenomenen die mogelijk gezien kunnen worden als een expressie van non-acceptatie. Wij richtten ons daarbij op specifieke "verwachtingen" ten aanzien van de toekomst van het dove kind en "opvattingen" over doofheid in het algemeen. We zochten daarnaast naar specifieke emoties, zoals teleurstelling, wrok, schaamte, medelijden en verdriet. Tot slot zochten wij naar specifieke gedragsuitingen, zoals afwijzing, ontwijking en het onvermogen een authentieke relatie met het dove kind aan te gaan. Ten aanzien van toekomst "verwachtingen" vonden wij dat ouders over het algemeen tamelijk bescheiden waren: ouders waren doorgaans terughoudend waar het vragen naar hun verwachtingspatroon betrof, en richtten zich meer op emotionele en relationele aspecten op korte termijn. Ondanks de bevinding dat het hebben van een doof kind grote verandering teweegbrengt en dat ouders die veranderingen niet altijd onvoorwaardelijk als positief ervaren, waren ouders niet teleurgesteld en koesterden zij zeker geen wrok. Ten aanzien van schaamte en

ontwijkinggedrag vonden wij dat ouders soms moeite hadden in het openbaar gebarentaal te gebruiken. Hoewel deze bevinding zou kunnen wijzen op schaamte en non-acceptatie, zijn er andere - minder belastende - mogelijke verklaringen. Ouders koesterden geen medelijden ten opzichte van hun kind, doch werden hier wel constant mee geconfronteerd in hun ontmoeting met anderen. Ouders beschouwden deze confrontatie als een aanval op de individualiteit van hun kind, en als een ontkenning van de liefdevolle relatie die zij met hun kind onderhouden. Desalniettemin vonden wij dat ouders bij tijd en wijlen konden treuren over de doofheid van hun kind. In tegenstelling tot het verdriet rondom de diagnose, betrof het hier echter een veel minder alomvattend verdriet dat bovendien nadrukkelijk werd ingevuld met de specifieke beperkingen die door de doofheid worden opgeworpen. Doordat het "wat" van de beperkende doofheid werd gescheiden van het "wie" van het existentiële en relationele kind, leidde deze vorm van verdriet niet tot medelijden. De bovenstaande bevindingen kwamen goed overeen met de specifieke beslissingen die door ouders genomen werden. Over het algemeen waren ouders goed voorbereid en ook in staat om beslissingen te nemen en verandering te ondergaan. Hoewel ouders vaak eenzijdige en onvolledige informatie ontvingen, kozen ze vrijwel unaniem voor gebarentaal. De primaire motivatie voor deze keuze was pragmatisch en emotioneel-relationeel: ouders wensten een communicatie medium dat snel en efficiënt kon worden aangewend om aldus de ouder-kind relatie te bevorderen, om het affectieve welzijn van hun kind te optimaliseren en om een geschikte omgeving te scheppen voor een jong kind. Sommige ouders deden echter een beroep op non-pragmatische casu quo principiële argumenten, waarbij doofheid werd voorgesteld als een identiteits- of cultuurkwestie. Deze argumentatie wordt door ons gekenmerkt als het Doven Cultuur Identiteit (DC-ID) discours. De meeste respondenten die een beroep deden op het DC-ID discours waren ouders van een kind dat verbonden was aan een primair gebarentaal georiënteerde school. Dit zou de suggestie kunnen wekken dat deze ouders "bewust" hebben gekozen voor een gebarenschool. Dit bleek echter over het algemeen geen valide hypothese, gezien het feit dat verreweg de meeste ouders hun schoolkeuze primair door geografische factoren lieten bepalen.

In hoofdstuk 5 beschrijven wij de ervaringen van ouders gedurende de schoolgaande leeftijd van hun doof kind. Een centraal thema waar wij ons op hebben gericht is de rol van dovenscholen en andere ouders van dove kinderen die men daar ontmoet, door ons de "Doven ecologie" genoemd. Gezien de asymmetrie tussen ouders en leerkrachten, het feit dat vooral ouders wiens kind op een gebarenschool zit zich beroepen op het DC-ID discours, het feit dat DC-ID argumenten een tamelijk abstract discours vormen, het gegeven dat ouders na verloop van tijd waarschijnlijk over meer kennis zullen komen te beschikken en gezien het feit dat een opgroeiend kind op den duur zelf een plaats zal opeisen in de overwegingen die ouders maken, is het interessant om te onderzoeken of en hoe het perspectief van ouders in de tijd verandert en hoe de interactie met de Doven ecologie hierop van invloed is. Onze gegevens illustreren dat dovenscholen, vooral de gebarentaal georiënteerde scholen, hun perspectief weinig veranderen met het vorderen van de tijd. Het belang van een "beschermende omgeving"

bleef een centraal thema, en werd op grond van socio-emotionele argumenten gelegitimeerd. Dove kinderen werden structureel afgebeeld als "speciale" en "kwetsbare" kinderen, die beschermd moeten worden van de buitenwereld en niet moeten worden blootgesteld aan al te uitdagende omstandigheden. Anderzijds werd het beschermend paradigma ondersteund met pragmatische argumenten, door te verwijzen naar de tragische geschiedenis van Dove volwassenen. Echter, het meest krachtige argument bleek te berusten op de voorstelling van doofheid als een "essentiële" eigenschap: de Doven cultuur werd voorgesteld als de enige cultuur waar dove kinderen toe "behoren", waaruit volgt dat zij het "recht" hebben binnen deze gemeenschap gesocialiseerd te worden. Ook het concept "acceptatie" speelde hierbij een hoofdrol. De suggestie werd gewekt dat het negeren van de voorschriften van de dovenschool als een symptoom van non-acceptatie moet worden opgevat, van "slecht" ouderschap en "intolerantie". Als zodanig werden ouders die hieraan twijfelden moreel veroordeeld en geïsoleerd. In tegenstelling tot dovenscholen, bleek dat het perspectief van ouders in de tijd aan verandering onderhevig was. Wij keken hiertoe primair naar de verhalen van ouders van kinderen die ten tijde van het interview tenminste 8 jaar oud waren. Hieruit bleek dat ouders langzaam afstand namen van hun primair sociaal-emotionele perspectief en steeds meer gericht raakten op de toekomstige behoeften en belangen van hun kind. Het abstracte DC-ID discours maakte bovendien plaats voor een veel meer pragmatisch en op het individuele kind gericht perspectief. Ouders bekritiseerden de voorstelling van dove kinderen als zijnde categorisch "kwetsbaar" op grond van de stigmatisering die van deze beeldvorming uitgaat en het potentieel negatieve effect daarvan op toekomstige behoeften en belangen. Bovendien vonden ouders dat deze voorstelling bepaald ontoepasselijk was in de context van hun individuele kind. Als gevolg van deze ontwikkeling creëerden ouders de morele ruimte om hun kind meer uitdagingen aan te bieden: gesproken taal, integratie in het reguliere onderwijs en blootstelling aan de horende samenleving waren hierbij centrale ingrediënten. Ouders waren echter niet ongevoelig voor de reële kwetsbaarheid en beperkingen van hun kind. Het actueel functioneren van hun kind was een graadmeter die constant werd geraadpleegd, en ouders waren zich doorlopend bewust van de mogelijkheid tot falen. Het feit dat sommige ouders besloten bepaalde veranderingen terug te draaien, ondersteunt deze stelling. Dovenscholen reageerden negatief op dit nieuwe pragmatische ouderlijke perspectief, door een verhevigd beroep te doen op het DC-ID discours. Op hun beurt reageerden ouders met een ontmanteling van dit discours. Ouders bekritiseerden het DC-ID discours als zijnde een cultureel "keurslijf" dat hun kind de ruimte ontnam zich naar eigen inzicht te ontplooien. Zij verzetten zich tegen de autoriteit van dovenscholen en verbraken de koppeling van het DC-ID discours met de morele status van hun ouderschap. Het resultaat van deze ontwikkeling beschrijven wij als de geboorte van het "eigenwijze", pragmatische en sterk op het belang van het kind gericht ouderschap.

In hoofdstuk 6 richten wij ons specifiek op het thema cochleaire implantatie. De meeste ouders werden zich pas geruime tijd na het stellen van de diagnose bewust van de mogelijkheid tot cochleaire implantatie. De informatie die zij tijdens het bezoek aan het

implantatie-team ontvingen, was doorgaans bescheiden van aard. Het implantatie team sprak vooral over de mogelijkheid van een verbeterde geluidsperceptie na implantatie, en vermeed het vooruitzicht van gesproken taal. De media daarentegen, waren veel uitbundiger en speculatiever in hun rapportage. Bovendien verwarden zij met enige regelmaat de implantatie van volwassen post-linguaal doven met de casus van pre-linguaal dove kinderen. Niettegenstaande de bescheiden informatie die ouders van implantatie teams ontvingen, was het enthousiasme van ouders doorgaans groot, hoewel niet kritiekloos. De Doven ecologie daarentegen, stelde zich vaak kritisch op ten opzichte van cochleaire implantatie. Dit was vooral het geval op gebarentaal-georiënteerde scholen. De argumenten tegen cochleaire implantatie waren min of meer gelijk aan de DC-ID kritiek welke eerder de revue passeerde. Meer specifiek richtte de kritiek zich op de vermeende twijfelachtige werkzaamheid van cochleaire implantatie. Wanneer ouders gevraagd werd waarom zij destijds voor cochleaire implantatie kozen, spraken veel ouders vooral over het vooruitzicht van een verbeterde geluidsperceptie en nauwelijks over gesproken taal. Bij doorvragen bleek echter dat de meeste ouders erkenden dat een verbeterde geluidsperceptie alléén, onvoldoende reden was om voor cochleaire implantatie te kiezen. Ouders koesterden wel degelijk de "hoop" dat cochleaire implantatie een positief effect zou hebben op de ontwikkeling van gesproken taal, en aldus op het verruimen van het toekomst perspectief van hun kind. De meeste ouders realiseerden zich terdege dat deze hoop voorbarig zou kunnen blijken te zijn, en hielden daarom de deur naar de Doven cultuur open. Een opvallende bevinding ten aanzien van de ouders die hun kind niet lieten implanteren was dat een meerderheid feitelijk nooit voor of tegen cochleaire implantatie had gekozen, gezien het feit dat de techniek simpel weg niet geschikt of beschikbaar was voor hun kind. Desalniettemin imponeerden controle-ouders over het algemeen als sceptischer ten opzichte van de vermeende werkzaamheid van cochleaire implantatie, en waren zij meer bezorgd over mogelijk negatieve neveneffecten. Enkele van deze ouders hanteerden het DC-ID discours in hun mening over cochleaire implantatie. Desalniettemin kregen wij niet de indruk dat dit discours van doorslaggevend belang was. De meeste ouders uit deze groep gaven te kennen dat ook zij onder bepaalde omstandigheden voor een cochleair implantaat zouden kiezen, waarmee zij impliciet te kennen gaven geen fundamenteel bezwaar tegen de techniek te hebben. De implantatie ingreep zelf werd door ouders niet als bijzonder belastend ervaren. Opvallend was dat ouders gedurende de begin periode van de revalidatie periode hun uiterste best deden het kind rustig te laten wennen aan de nieuwe situatie, om aldus aversie te voorkomen. De vroege implantatie resultaten bleven doorgaans beperkt tot een bescheiden verbetering van geluidsperceptie, en de resultaten werden vaak pas na verloop van tijd merkbaar. Desalniettemin reageerden ouders vaak positief. Een analyse van de ervaringen van ouders van meer ervaren kinderen (tenminste 18 maanden ervaring met cochleaire implantatie) liet zien dat de resultaten van cochleaire implantatie over een tijdspanne van enkele jaren gelijkelijk aan tot uitdrukking komen. Na verloop van tijd leerden de meeste kinderen de gesproken taal beheersen, hoewel de mate waarin nogal wisselde. Het verbeteren van vaardigheden in de gesproken taal was regelmatig aanleiding om het aanbod aan gebarentaal enigszins af te bouwen en

integratie in het reguliere onderwijs te overwegen. Hoewel ouders doorgaan tevreden waren met de lange termijn resultaten van cochleaire implantatie, bleef men "hopen" op nog betere resultaten en bleef men de toekomst als onzeker bezien.

In hoofdstuk 7 trachten wij de meest geschikte morele ruimte te definiëren om cochleaire implantatie bij kinderen vanuit moreel en ethisch perspectief nader te analyseren. Centraal hierbij staat het DC-ID discours. Ondanks het feit dat de meeste ouders het DC-ID discours afwijzen, kunnen wij deze positie niet zondermeer overnemen. Aan de andere kant, indien dit discours als het meest toepasselijk wordt bevonden, is een verdere pragmatische analyse van cochleaire implantatie overbodig. Het DC-ID discours beweegt zich rond het begrip "acceptatie", echter zoals wij hebben laten zien is dit een meerduidig begrip. (Non-) acceptatie is een belangrijk element van de copingtheorie. Mensen kunnen, omdat zij bepaalde omstandigheden niet accepteren, beslissingen nemen die een onvoordelige uitwerking hebben. In het geval van ouders van een gehandicapt kind vertaalt deze theorie zich naar de mogelijkheid dat non-acceptatie een "pathologische" coping op gang kan brengen, hetgeen in kan houden dat ouders beslissingen nemen die ongunstig uitpakken ten aanzien van het belang van hun kind. Naar ons inzicht is deze these niet zondermeer van toepassing op de ouders in deze studie. Een meer gecompliceerde kwestie betreft de verwijzing van het begrip "acceptatie" naar de morele attitude van ouders als zijnde "onvoorwaardelijk" liefhebbend. Merkwaardig in dit geval is dat de Doven ecologie niet alleen een beroep doet op dit moreel concept, maar tevens de invulling ervan bepaalt. Door zo expliciet de spelregels van "acceptatie" te definiëren, werpt de Doven ecologie zich op als moreel instituut. De meest fundamentele aanval op cochleaire implantatie wordt gevormd door het Doven cultuur discours, welke een sterke verwijzing inhoudt naar de discussie rond etnische en raciale minderheden. Dit discours is door Lane verwoord in zijn afwijzing van de hypothetische casus van een "perfect" implantaat. De aard van Lane's argumentatie komt grotendeels overeen met het betoog tegen een eis tot aanpassing met betrekking tot etnische minderheden. Deze laatste argumentatie wordt in detail besproken en wij komen tot de conclusie dat de toepasbaarheid daarvan op de casus van cochleaire implantatie niet zondermeer opgaat. Desalniettemin moet het strategische voordeel van een fundamenteel Doven cultuur discours onderkend worden: dit discours kan worden opgevat als een "tegenstroming", die ongebreideld enthousiasme over cochleaire implantatie tot meer reële proporties kan terugbrengen. Wij concluderen dan ook dat het Doven discours in feite een politiek discours is, wat primair bedoeld is om deze strategische functie te vervullen. Het gevaar van zo'n fundamenteel discours is echter dat dit strategische doel uit het oog verloren raakt, waardoor het een eigen leven gaat leiden en aldus een dwingend en alomvattend karakter krijgt. Zo'n ontwikkeling zal het belang van dove kinderen eerder schaden dan bevorderen. Wij menen dan ook dat de argumenten van het fundamentele Doven discours binnen een ethische analyse ontoereikend is en niet kan worden opgevat als een argument om verdere analyse van het probleem op te schorten. Het is naar ons inzicht wenselijk de casus cochleaire implantatie nader uit te werken op geleide van het belang ("best-interest") van het kind. Voordat

hiertoe kan worden overgegaan is het van doorslaggevend belang nadere invulling te geven aan het begrip "best-interest", zowel vanuit conceptueel als theoretisch perspectief Deze behoefte is aanleiding tot een bespreking van de literatuur die hierover is gepubliceerd Liberale theorieen beschrijven het belang van het kind doorgaans hoofdzakelijk in termen van de vrijheid het toekomstig leven naar eigen inzicht te kunnen inrichten Om dit redelijkerwijs te kunnen realiseren, moet aan bepaalde basis voorwaarden worden voldaan Sommige "extreem" liberale denkers, menen dat dit "recht" op een "open toekomst" letterlijk moet worden opgevat, hetgeen tot de conclusie kan leiden dat ouders de plicht hebben de vrijheid en kansen van hun kind te "optimaliseren" Anderen menen echter dat zo'n eis buitensporig is, en bijvoorbeeld geen rekening houdt met de belangen-verbondenheid van ouder en kind Als alternatief wordt er gesteld dat ouders niet perse hoeven te streven naar een maximale vrijheid of optimale kansen, maar wel "redelijkerwijs" - dat wil zeggen, binnen hun "redelijke" mogelijkheden - rekening moeten houden met keuzes die hun kind "redelijkerwijs" zou kunnen maken in de toekomst De rechtszaak die de staat Wisconsin in 1972 aanspande tegen de Amish, illustreert dat het specifiek invullen van deze criteria zelfs in het geval van gezonde kinderen een complexe en omstreden kwestie is In het geval van gehandicapte kinderen neemt de complexiteit louter toe hoe moeten wij "redelijke" levensvooruitzichten definieren waar het dove kinderen betreft? Critici menen bijvoorbeeld dat slechts de biografie van volwassen Doven hiervoor een maatstaf kan zijn Wij menen echter dat deze voorstelling van zaken tekort schiet, en als zodanig onvoldoende reden is om niet te streven naar een bredere definitie van een "redelijk" levensvooruitzicht Toch blijft de toepasbaarheid van het liberale "best-interest" paradigma in het geval van gehandicapte kinderen een probleem De casus van ernstig geretardeerde kinderen en chronisch psychiatrische patienten illustreren de beperkingen van zo'n visie Wanneer we de autonomie om zelfstandig een levenspad te kunnen bepalen opvatten als de centrale waarde binnen een best-interest analyse, stoten we bij deze twee groepen evident op problemen Onder bepaalde omstandigheden kan het beperken van deze keuze-vrijheid uiteindelijk meer profijt opleveren De waarden van "zorg" en "sociaal-emotioneel welzijn" worden bijvoorbeeld niet adequaat in het extreem liberale model meegewogen, terwijl het belang daarvan bij ernstig geretardeerde kinderen tamelijk vanzelfsprekend is Ondanks dit gegeven, dreigt achter deze vanzelfsprekendheid het gevaar van paternalisme, in de vorm van een dwingende en alomvattende "zorg ideologie" Dit gevaar neemt toe in het geval van handicaps waarbij de mogelijkheden tot autonomie groter zijn dan in het geval van ernstige retardatie Aldus menen wij dat het ongewenst is om de morele ruimte in het geval van dove kinderen a-priori in te perken tot "zorg", zoals aan sommige dovenscholen schijnbaar het geval is Desalniettemin vinden wij het negeren van de reele beperkingen van dove kinderen en het negeren van het belang van zorg en sociaal-emotioneel welzijn evenzo onwenselijk Wij komen aldus tot de conclusie dat de meest redelijke benadering van het "belang" van een doof kind rekening zou moeten houden met zowel "liberale" waarden als autonomie, alsook "communitaristische" waarden als zorg en sociaal-emotioneel

welzijn. Op grond van ons materiaal concluderen wij dat ouders hier, in de zin van hun algemene "attitude", prima aan voldoen.

In hoofdstuk 8 presenteren wij onze uiteindelijke analyse van het cochleaire implantatie debat. Hiertoe is het noodzakelijk om de specifieke merites van zowel cochleaire implantatie als het Doven cultuur alternatief grondig onder de loep te nemen. Wij laten ons bij deze analyse leiden door de gedachte dat voorstanders van beide opties uitgaan van specifieke best-interest argumenten, die schetsmatig gevat kunnen worden in een kosten-baten model. Hoewel empirische data ongetwijfeld een ingrediënt zijn van zo'n model, moet men ook rekening houden met retorica en wellicht zelfs paradigmatische vooroordelen. Wij trachtten de argumenten te beschrijven binnen het kader van een kosten-baten model. Een centraal thema dat hierbij niet ontzien kan worden, is de globale kritiek die over de jaren heen geuit is op het zogenaamde "klassieke" medische kosten-baten model model. Een van de meest bekritiseerde punten van dit model is dat het de neiging heeft om fysiologisch "effect" zonder meer gelijk te stellen aan "baat". Wij werken deze kritiek uit aan de hand van het voorbeeld van levensreddende medische behandelingen, en concluderen dat het klassiek medisch kosten-baten model het gevaar inhoudt over te gaan in een zichzelf legitimerende "rug-tegen-de-muur" filosofie. Wij vinden het wenselijk dat bij de evaluatie van het nut van medische behandelingen verder wordt gekeken dan dit paradigma. Aldus houden wij een pleidooi voor een bredere benadering van een kosten-baten analyse, waarbij "baat" voorbij fysiologisch effect wordt opgevat, en waarbij zowel succesvolle als niet-succesvolle behandelingen alsook het alternatief van non-interventie expliciet worden meegewogen. Deze benadering wordt vervolgens op de casus cochleaire implantatie toegepast. Een "rug-tegen-de-muur" filosofie is in het geval van cochleaire implantatie niet van toepassing, gezien het feit dat het non-interventie alternatief niet eens bij benadering zo nihilistisch is als in het geval van levensreddende ingrepen. Verder stellen wij dat "niet horen" in zichzelf een secundair probleem is, in verhouding tot de omvang van de problematiek waar een pre-linguaal doof kind zich voor gesteld ziet. Op basis hiervan concluderen wij dat niet elke vorm van "effect" een voldoende legitimatie is voor cochleaire implantatie en beargumenteren wij dat een meer detaillistische analyse van kosten en baten op zijn plaats is. Dat betekent dat wij de kosten-baten analyse van cochleaire implantatie breder moeten opvatten dan audiologische parameters alleen. Uiteindelijk moet "baat" in het geval van cochleaire implantatie gezien worden in termen van de verbeterde mogelijkheden tot ontwikkeling van gesproken taal en, uiteindelijk, verbeterde mogelijkheden in de toekomst. Wij menen dat dit in feite ook de premisse is van implantatie teams, ook al wordt dat zelden expliciet zo uitgesproken. Na deze definitie van "baat" gaan wij voort met het analyseren van de kosten en baten van "succesvolle" implantaties, "onsuccesvolle" implantaties en het non-interventie alternatief van Doven cultuur. Wij komen tot de conclusie dat cochleaire implantatie een waardevolle bijdrage kan leveren aan de belangen van een doof kind, echter dat enkele condities hierbij van fundamenteel belang zijn. Vooral het lot van "onsuccesvolle" implantaties hebben een belangrijke invloed op de kosten-baten analyse. Onsuccesvolle

implantaties, gedefinieerd als geïmplanteerde individuen die het apparaat niet langer gebruiken, zullen waarschijnlijk gaan optreden. Implantatie teams doen er verstandig aan de factoren die tot falen aanleiding geven te identificeren, zodat kandidaten in de toekomst beter geselecteerd kunnen worden. Behalve het terugdringen van de incidentie van onsuccesvolle implantaties is het evenzeer van belang de omvang van "kosten" zo veel mogelijk te beperken. Dat betekent dat geïmplanteerde kinderen vele jaren vervolgd zouden moeten worden, en dat de bereidheid en mogelijkheid moet bestaan om bijtijds het roer om te gooien. Concreet betekent dit dat axioma's verlaten moeten worden en vervangen moeten worden door een pragmatische benadering. Het betekent ook dat implantatie teams een goede werkrelatie moeten onderhouden met gespecialiseerde dovenscholen. Omgekeerd dienen ook dovenscholen hun ideologische positie te verlaten, wil zo'n samenwerking een kans van slagen hebben om aldus het belang van het dove kind serieus te behartigen.

Deze studie illustreert dat het "belang" van dove kinderen een complexe zaak is en naar een ambivalente werkelijkheid verwijst. Gedurende meer dan tweehonderd jaar is dit schijnbaar aanleiding geweest zich terug te trekken in extreme ideologische posities. Vandaag de dag staan we voor een unieke historische uitdaging. Gebarentaal is niet langer een ondergeschoven kind en wordt thans aan veel dovenscholen onderwezen. Tegelijkertijd hebben wij thans de beschikking over een techniek die, voor het eerst in de geschiedenis, sommige dove kinderen daadwerkelijk de toegang tot gesproken taal verschaft en aldus hun toekomstige mogelijkheden kan verruimen. Als zodanig kan de waarde van de gesproken taal niet langer op basis van het ontbreken van reële mogelijkheden verworpen worden, en staan wij voor de uitdaging een synthese te zoeken. Wij menen dat een pragmatische en kind-gerichte benadering, in dit kader een uitstekende optie is. Wij zijn er in ieder geval van overtuigd dat dit de weg is die we moeten inslaan, als we onze verantwoordelijkheid naar dove kinderen toe serieus nemen.

APPENDIX

APPENDIX I: CHARACTERISTICS CASES

C1a

• Sex	female
• Age at interview	12.5 years
• Age deaf	33 months
• Age diagnosis	6 weeks later
• Cause deaf	meningitis
• Age implantation	5
• Siblings	3
• Rank	1
• SES	1
• Area	South-east
• School initially	hard of hearing
• School at interview	mainstreamed
• Dominant language home < CI	spoken language
• Dominant language home > CI	spoken language
• Time elapsed since CI	7.5 years
• Active in advocacy etc	yes

C2b

• Sex	female
• Age at interview	5
• Age deaf	birth
• Age diagnosis	10 months
• Age implant	3 years 8 months
• Cause deaf	probably congenital
• Siblings	1 brother
• Rank	1
• SES	1
• Area	South-east
• School initially	oral school for deaf
• School at interview	oral school for the deaf
• Dominant language home < CI	sign language
• Dominant language home > CI	sign language and spoken language
• Time elapsed since CI	1.5 years
• Active in advocacy etc	no

C3b

- Sex: male
- Age at interview: 14 years
- Age deaf: 6 months
- Age diagnosis: 8 months
- Age implantation: 9 years 3 months, partial insertion
- Cause deaf: probably meningitis
- Siblings: 3
- Rank: 3
- SES: 1
- Area: South-east
- School initial: cued speech IvD
- School at interview: special deaf education IvD (VSO)
- Dominant language home < CI: fingerspelling
- Dominant language home > CI: fingerspelling
- Time elapsed since CI: 5 years
- Active in advocacy etc: no

C4ab

- Sex: female
- Age at interview: 10 years
- Age deaf: 2 years 10 months
- Age diagnosis: 2 years 11 months
- Age implantation: 5 years 4 months
- Cause deaf: meningitis
- Siblings: 2
- Rank: 3
- SES: 2
- Area: South-east
- School prior CI: hard of hearing
- School at interview: mainstreamed
- Dominant language home < CI: oral
- Dominant language home > CI: oral
- Time elapsed since CI: 5 years
- Active in advocacy etc: no

C5a

- Sex: male
- Age at interview: 11 years 11 months
- Age deaf: 2 years 6 months
- Age diagnosis: 2 years 6 months, about 2 weeks later

- Age implantation 6 years 6 months
- Cause deaf meningitis
- Siblings 1
- Rank 1
- SES 2
- Area Western
- School prior CI signing deaf
- School at interview mainstreamed
- Dominant language home < CI sign
- Dominant language home > CI sign and spoken language
- Time elapsed since CI 6 years
- Active in advocacy etc yes

C6

- Sex female
- Age at interview 12
- Age deaf birth
- Age diagnosis 4 months
- Age implantation 8 years 2 months
- Cause deaf congenital genetic
- Siblings 2
- Rank 3
- SES 1
- Area northern
- School prior CI signing deaf
- School at interview signing deaf
- Dominant language home < CI sign
- Dominant language home > CI sign and spoken language
- Time elapsed since CI 4 years
- Active in advocacy etc yes

C7a

- Sex female
- Age at interview 11 years
- Age deaf 32 months
- Age diagnosis 32 months, about 2 weeks later
- Age implantation 6 years 6 months, partial insertion
- Cause deaf meningitis
- Siblings 2
- Rank 1
- SES 1

- Area northern
- School prior CI deaf signing
- School at interview deaf signing
- Dominant language home < CI sign and speech
- Dominant language home > CI sign and speech
- Time elapsed since CI 5 years
- Active in advocacy etc yes

C8b

- Sex male
- Age at interview 5 years 6 months
- Age deaf birth
- Age diagnosis 13 months
- Age implantation 4 years 9 months
- Cause deaf congenital
- Siblings 1
- Rank 1
- SES 1
- Area south-east
- School prior CI hard of hearing
- School at interview hard of hearing
- Dominant language home < CI sign
- Dominant language home > CI sign and some spoken language
- Time elapsed since CI 6 months
- Active in advocacy etc no

C9a

- Sex female
- Age at interview 13 years
- Age deaf 2 years 10 months
- Age diagnosis 2 years 10 months, about 2 weeks later
- Age implantation 5 years 3 months
- Cause deaf meningitis
- Siblings 1
- Rank 1
- SES 2
- Area northern
- School prior CI signing deaf followed by oral deaf
- School at interview mainstreamed
- Dominant language home < CI sign language
- Dominant language home > CI spoken language

- Time elapsed since CI 8 years
- Active in advocacy etc yes

C10ab

- Sex Female
- Age at interview 10
- Age deaf 2 years 8 months
- Age diagnosis 2 years 10 months
- Age implantation 6 year two months, partial insertion
- Cause deaf meningitis
- Siblings 4
- Rank 4
- SES 1
- Area northern
- School prior CI signing deaf
- School at interview mainstreamed
- Dominant language home < CI spoken language, fingerspelling and sign
- Dominant language home > CI spoken language, fingerspelling and sign
- Time elapsed since CI 4
- Active in advocacy etc no

C11

- Sex male
- Age at interview 9
- Age deaf 18 months
- Age diagnosis 21 months
- Age implantation 5 years 11 months
- Cause deaf meningitis
- Siblings 1
- Rank 2
- SES 3
- Area northern
- School prior CI signing deaf
- School at interview sign deaf, now mainstreamed with translator
- Dominant language home < CI sign
- Dominant language home > CI sign
- Time elapsed since CI 3 years
- Active in advocacy etc yes

C12ab

- Sex male
- Age at interview 10
- Age deaf 2 years 4 months
- Age diagnosis 2 years 5 months
- Age implantation 5 years 8 months
- Cause deaf meningitis
- Siblings 2
- Rank 1
- SES 2
- Area northern
- School prior CI deaf signing
- School at interview deaf signing
- Dominant language home < CI sign
- Dominant language home > CI sign
- Time elapsed since CI 5 years
- Active in advocacy etc no

C13

- Sex female
- Age at interview 4 years, 3 months
- Age deaf birth
- Age diagnosis about 22 months
- Age implantation 2 years, 10 months
- Cause deaf probably congenital
- Siblings 2
- Rank 2
- SES 3
- Area western
- School prior CI deaf signing
- School at interview deaf signing
- Dominant language home < CI sign
- Dominant language home > CI sign
- Time elapsed since CI 1 year, 5 months
- Active in advocacy etc yes

C14b

- Sex Male
- Age at interview 3.5 years
- Age deaf birth
- Age diagnosis 11 months

- Age implantation 2 years 10 months
- Cause deaf probably congenital
- Siblings 2
- Rank 2
- SES 2
- Area western
- School prior CI signing deaf
- School at interview hard of hearing
- Dominant language home < CI sign language
- Dominant language home > CI sign language
- Time elapsed since CI 6 months
- Active in advocacy etc no

C15

- Sex Female
- Age at interview 10 years
- Age deaf 3 months
- Age diagnosis about 3 years
- Age implantation 6 years 3 months
- Cause deaf meningitis
- Siblings 1
- Rank 1
- SES 2
- Area western
- School prior CI signing deaf
- School at interview signing deaf
- Dominant language home < CI sign language
- Dominant language home > CI sign language
- Time elapsed since CI 4 years
- Active in advocacy etc yes, active in school

C16b

- Sex Male
- Age at interview 8
- Age deaf probably birth
- Age diagnosis 30 months
- Age implantation 6 years 8 months
- Cause deaf probably congenital
- Siblings 1
- Rank 2
- SES 1

- Area south-east
- School prior CI oral deaf IvD
- School at interview signing hard of hearing
- Dominant language home < CI sign language
- Dominant language home > CI sign language
- Time elapsed since CI 1.5 years
- Active in advocacy etc no

APPENDIX II: CHARACTERISTICS CONTROLS

CO1

- Sex: male
- Age at interview: 8
- Age deaf: 0
- Age diagnosis: unknown
- Cause deaf: probably congenital
- Siblings: 0
- Rank: 1
- SES: 3
- Area: Northern
- Initial school: signing deaf
- School at interview: signing deaf
- Dominant language home: sign
- Active in advocacy: yes

CO2

- Sex: female
- Age at interview: 9
- Age deaf: 12 months
- Age diagnosis: about 12 weeks later
- Cause deaf: meningitis
- Siblings: 2
- Rank: 2nd
- SES: 2
- Area: South-east
- Initial school: signing hard of hearing
- School at interview: signing hard of hearing
- Dominant language home: sign and spoken language
- Active in advocacy: yes

CO3

- Sex: male
- Age at interview: 17 and 13
- Age deaf: birth
- Age diagnosis: 18 months
- Cause deaf: probably congenital
- Siblings: 3 children in total
- Rank: 1 and 3

- SES 3
- Area South-east
- Initial school signing hard of hearing
- School at interview mainstreamed
- Dominant language home spoken language
- Active in advocacy yes

CO4b

- Sex female
- Age at interview 6 years
- Age deaf 6 months
- Age diagnosis 7 months
- Cause deaf meningitis
- Siblings 1
- Rank 2
- SES 1
- Area northern
- School signing deaf
- Dominant language home sign
- Active in advocacy etc no

CO5b

- Sex male
- Age at interview 10
- Age deaf birth
- Age diagnosis 10 months
- Cause deaf congenital
- Siblings 1
- Rank 2
- SES 2
- Area south-east
- Initial school oral deaf
- School mainstreamed
- Dominant language home spoken language
- Active in advocacy etc no

CO6b

- Sex female
- Age at interview 7 years
- Age deaf 16 months

- Age diagnosis: 4 months later
- Cause deaf: meningitis
- Siblings: 1
- Rank: 2
- SES: 1
- Area: south-east
- School: hard of hearing sign
- Dominant language home: sign language
- Active in advocacy etc: no

CO7

- Sex: female
- Age at interview: 15 and 11
- Age deaf: birth
- Age diagnosis: about 12 months and about 8 months
- Cause deaf: congenital
- Siblings: 1
- Rank: 1 and 2
- SES: 2
- Area: western
- School: mainstreamed (eldest) and signing deaf (youngest)
- Dominant language home: sign language
- Active in advocacy etc: yes

APPENDIX 3: INTERVIEW PROTOCOL

VU/KUN

KWALITATIEF PEDIATRISCH COCHLEAIRE IMPLANTATIE PROJECT

Interview schema ouders

Inleiding

1. Introductie interviewer

2. Formuleren doel van gesprek
   * doel: inzicht in afwegingen rond CI
   * methode: semi-gestructureerde interviews
   * anonieme verwerking
   * privacy
   * recht om van interview af te zien

Vragen Ouders algemeen

ik zou graag willen beginnen met u wat algemene vragen te stellen

3. Leeftijd ouders?
   * Moeder:
   * Vader:

4. Huidige opleiding of hoogst genoten opleiding:
   geen
   basis of lagere school
   lager beroepsonderwijs (lbo, lts)
   middelbaar algemeen onderwijs (ulo, lavo, mavo)
   middelbaar beroepsonderwijs ([k]mbo, leerlingwezen)
   voorgezet algemeen onderwijs (havo, vwo)
   hoger beroepsonderwijs (hbo, heao, hts)
   hoger algemeen en wetenschappelijk onderwijs

5. Burgerlijke staat functionele ouders[1]?

[1] Gedefinieerd als duo wat ten tijde van de geboorte van het kind verantwoordelijk was voor de zorg.

gehuwd/samenwonend
gescheiden vòòr cochleaire implantatie
gescheiden ná cochleaire implantatie
ander

6. Gezinsvorm
   twee-ouder-gezin
   één-ouder-gezin
   complex gezin
   * inwonende familie
   * woongroep

7. Was u enigerlei bekend met "doofheid" voor de geboorte van uw kind?
   ja nee
   * beschrijven

8. Was u bekend met "handicap" voor de geboorte van uw kind
   ja nee
   * beschrijven

Vragen kind algemeen

ik zou willen vervolgen met enkele algemene vragen over uw kind

9. Naam van kind

10. Geslacht kind man vrouw

11. Geboortedatum kind __/__/__

12. Andere kinderen? ja nee
    * Hoeveel?

13. Andere dove kinderen? ja nee
    * beschrijven

14. Andere kinderen met een handicap?
    * beschrijven

15. Geboorterang kind?

16. Oorzaak doofheid?

aangeboren
meningitis
andere
onbekend bij ouder
onbekend bij medici & ouder

17. Plotseling doof, of eerst slechthorend?

18. Als aangeboren:
    * leeftijd diagnose doofheid

19. Als verworven doofheid:
    * vermoedde leeftijd ontstaan:
    * leeftijd diagnose:
    * hoe was de taalontwikkeling van het kind vòòr de doofheid?

20. Amplificatiegeschiedenis kind?
    * heeft uw kind ooit een gehoorapparaat gehad?
    * zo ja, werd daarmee enig resultaat geboekt?

21. Bijkomende handicaps? ja nee
    * beschrijven

22. Bijkomende gedragsstoornissen, leerstoornissen? ja nee
    * beschrijven

23. Bijkomende medische condities? ja nee
    * beschrijven

24. Educatieve geschiedenis kind?

Rond de Diagnose

ik zou graag een heel eind terug willen gaan in de tijd.

26. Normale zwangerschap?
    * moeizame zwangerschap?
    * IVF?
    * afloop vorige zwangerschappen?

27. Heeft u in de eerste maanden na de geboorte iets gemerkt aan .....?

28. Kunt u ingaan op de communicatie met uw kind vòòr de diagnose?
    * kwantiteit was dat voldoende?
        - hoeveelheid
        - tempo
    * kwaliteit was dat voldoende?
        - had u het gevoel dat u "contact" kon maken met uw kind?
        - had u het gevoel dat er sprake was van "communicatie": van
        - zou u deze communicatie als "complex" bestempelen of simpel, uiteraard rekening houdend met de leeftijd?
        - had u het gevoel dat er sprake was van een affectieve relatie: van een relatie waarin u uw emoties kenbaar kon maken en tegemoet kon komen aan de emotionele behoeften van het kind?
        - spontaneïteit
    * vorm/modaliteit (spraak, manueel)

	primair oraal	primair gebaren	combinatie
Vader			
Moeder			
Broer/zus			
Opa/Oma			
Familie			
Dove vrienden			
Horende vrienden			
Vreemden			

29. Heeft u ooit het gevoel gehad iets verkeerd te doen m.b.t. de communicatie?

30. Wanneer heeft u voor het eerst gemerkt dat er iets mis was met uw kind?
    * Hoe oud was uw kind toen?
    * Wat merkte u toen?
    * Welke oorzaak vermoedde u?
    * Heeft u hierover met anderen gesproken?
        ~wat was hiervan het resultaat?

31. Wanneer bent u met uw vermoedens naar een dokter gegaan?
    * Kunt u daar wat over vertellen?

32. Kunt u wat vertellen over het moment van de diagnose?

33. Wat wist u ten tijde van de diagnose iets van het leven van doven?
    * sociaal-maatschappelijke positie?
    * dovengemeenschap?
    * medium: ervaring, film, literatuur?

34. Kunt u samenvatten wat u is verteld tijdens het diagnostisch gesprek?
    * aangeraden communicatief beleid + morele kaders
    * aangeraden educatief beleid + morele kaders
    * informatie over toekomst perspectief: sociaal, emotioneel, maatschappelijk + morele kaders
        ~ koppeling educatief beleid aan sociaal scenario?
    * informatie over dovengemeenschap + morele kaders

    * advies tot nemen van contact dovengemeenschap
        ~ wat voor informatie
    * onmiddellijk informatie over CI gegeven?

35. Bent u nog elders geweest voor informatie, bv. voor second opinion?
    * waar?
    * aangeraden communicatief beleid + morele kaders
    * aangeraden educatief beleid + morele kaders
    * informatie over toekomst perspectief: sociaal, emotioneel, maatschappelijk + morele kaders
    * informatie over dovengemeenschap + morele kaders
    * advies tot nemen van contact dovengemeenschap
        ~ wat voor informatie
    * onmiddellijk informatie over CI gegeven?

36. Wat was uw reactie op de diagnose en de bijbehorende adviezen?

37. Hoe zag u de toekomst van uw kind onmiddellijk na de diagnose?
    * met betrekking tot communicatie met anderen?
    * met betrekking tot maatschappelijk functioneren?
    * met betrekking op kans op opleiding en carrière?
    * met betrekking op emotionele leven en relatievorming?
        ~relatie met dove, horende, geen verschil

38. Wat was de reactie van anderen op de diagnose?
    * familie: opa & oma
    * vrienden

39. Heeft u de informatie als consistent, helder en genuanceerd ervaren?

40. Heeft u tijdens de gesprekken het gevoel gehouden dat u elke keuze die u de juiste vond ook kon maken?

41. Had u het gevoel dat u uiteindelijk ook in staat was tot het nemen van een juiste beslissing of hebben anderen voor u besloten?
    * voelde u zich, emotioneel en rationeel, voldoende toegerust om tot een gewogen besluit te komen?
    * heeft u zich primair laten leiden door de adviezen van anderen (welke)?

Keuzes

Ik zou graag wat dieper willen ingaan op de besluiten die u destijds heeft moeten nemen

42. Heeft u zich bij uw besluit laten leiden door het directe belang van uw kind, door het belang van uw kind op de lange termijn, beiden?
    * onmiddellijke belang communicatie, emotionele ouder-kind binding
    * belang op de langer termijn cognitieve ontwikkeling, opleiding psycho-emotionele ontwikkeling, maatschappelijke ontwikkeling
    * ideologisch belang emancipatie doven, verschillende sociale scenario's
    * belang van anderen dovengemeenschap, gezin, broers/zusjes, ouders

Rol emotionele binding

43. **Heeft u het belang van een optimale ouder-kind communicatie overwogen?**

44. **In hoeverre heeft u dit actief onderzocht en hoe?**
    *** contacten met "ervaringsdeskundigen" (doven, onderwijsdeskundigen)?**
    *** literatuur (autobiografisch, professioneel)**

45. **Zijn dit zwaarwegende argumenten geweest?**

46. **Vond/vindt u gebarentaal een serieus alternatief?**
    *** had u moeite met het idee dat uw kind in gebarentaal zou communiceren?**
    ~kunt u dat verklaren?

Indien rol sociale scenario's

47. Heeft u de verschillende sociale scenario's expliciet overwogen?
    * leven in dovengemeenschap plus waardering
    * leven zo veel mogelijk in horende gemeenschap plus waardering
    * leven in beide gemeenschappen plus waardering

48. In hoeverre zijn de verschillende sociale scenario's actief onderzocht
    * contacten met dovengemeenschap gehad en waardering?
    * contacten gehad met dovenclubs etc?
    * contacten gehad met geïntegreerde kinderen en waardering?
    * literatuur (autobiografisch, professioneel)

49. Zo ja, welke rol hebben deze scenario's in uw afwegingen gespeeld?

50. Vond/vindt u een leven in de dovengemeenschap een serieus alternatief?

51. Heeft u actief contact gezocht met andere ouders van dove kinderen?

52. Heeft u contact gehad met een oudervereniging van ouders van dove kinderen?
    * welke?

53. Als geen contact met de dovengemeenschap, waarom wel/niet?
    * angst tot afwijzing door doven etc?

54. Wat is de inbreng geweest van familie en vrienden op de besluitvorming?
    * rol opa/oma

55. Waar heeft u toen uiteindelijk voor gekozen?
    * ten aanzien van communicatie met kind
        ~spraak/oraal-visueel
        ~spraak/oraal-visueel plus vingerspelling
        ~spraak/oraal-visueel plus vingerspelling plus gebaren (TC)
        ~gebaren
    * ten aanzien van educatieve planning
    * ten aanzien van socialisatie
        ~contact opgezocht andere dove kinderen, dove volwassenen, doven instituut
        ~bestaat er een verwantschap tussen uw sociale ideaal en uw communicatie-keuze?

56. Wat heeft u gedaan om uw voornemens uit te voeren?
    * heeft u zelf een gebarentaal cursus gevolgd en wanneer?
        ~beide ouders?
    * socialisatie kind

57. Was uw besluit een unaniem/gezamenlijk (was er consensus)?

58. Vond u het een moeilijke beslissing?
    * toelichting

59. Was dit in retrospect een moeilijke tijd voor het gezin?
    * echtelijke problemen
    * te weinig aandacht andere kinderen
    * verhouding met vrienden en familie?

60. Heeft u achteraf ooit twijfels gehad over de juistheid van uw besluit?

61. Maakte u zich wel eens zorgen over wat uw kind in de toekomst van uw beslissing zou gaan vinden?

62. Heeft u ooit schuldgevoelens gehad ten opzichte van uw doof kind?

63. Bent u in retrospect van mening dat er één ideaal beleid bestaat voor alle dove kinderen?

Communicatie

ik zou nu graag wat dieper willen ingaan op de communicatie met uw nu

64. Communicatie met kind & motivatie (modaliteit)
    * spraak/oraal-visueel
    * spraak/oraal-visueel plus vingerspelling
    * spraak/oraal-visueel plus vingerspelling plus gebaren (TC)
    * gebaren

	primair oraal	oraal + vinger	TC	primair gebaren
Vader				
Moeder				
Broer/zus				
Familie (Opa/Oma)				
Dove vrienden				
Horende vrienden				
Vreemden				

* als gebaren: ook wel eens gesproken taal?
* als oraal: ook wel eens gebaren?

Nu zou ik graag wat meer willen weten over de communicatie tussen u en uw kind nu

65. Communicatie: kwantiteit
    * vaak is dat voldoende?
    * soms is dat voldoende?
    * zelden is dat onvoldoende?
    * nooit

66. Communicatie: kwaliteit
    * heeft u het gevoel dat u "contact" kunt maken met uw kind?
    * heeft u het gevoel dat er sprake is van "communicatie": van wederzijds begrip over het "doel" of onderwerp van het contact?
    * zou u deze communicatie als "complex" bestempelen of simpel, uiteraard rekening houdend met de leeftijd?
    * heeft u het gevoel dat er sprake is van een affectieve relatie: van een relatie waarin u uw emoties kenbaar kunt maken en tegemoet kunt komen aan de emotionele behoeften van het kind?
    * spontaneïteit

67. Communicatie kwaliteit: communicatie breakdowns
    * begrijpt u altijd wat uw kind wil zeggen?
        ~moet u wel eens om een herhaling vragen?
        ~hoe reageert u hierop?
        ~hoe reageert uw kind hierop?
        ~wat doet u hieraan ter preventie
    * begrijpt uw kind altijd wat u wilt zeggen?

~moet uw kind wel eens om een herhaling vragen?
~hoe reageert u hierop?
~wat doet u hieraan ter preventie

* "mist" uw kind wel eens informatie?
  ~informele informatie, groepsgesprekken, horende vrienden etc
  ~wat doet u hieraan ter preventie
* zijn er wel eens zaken die moeilijk zijn over te dragen?
  ~complexe informatie, toekomstige gebeurtenissen etc.
  ~hoe gaat u hiermee om

68. Kunt u ook complexere zaken, zoals aangaande het emotionele leven, bespreken?
    * vergelijken met andere kinderen

69. Heeft u het gevoel dat ook uw kind dit goed met u kan bespreken?
    * vergelijken met andere kinderen

70. Voelt u zich wel eens buitengesloten in de communicatie met uw kind als gevolg van gebrekkige communicatie?
    * verschillen vader/moeder

71. Heeft u wel eens het gevoel dat uw kind zich buitengesloten voelt?
    * aan de eettafel, op familie feestjes etc

Nu zou ik graag wat meer willen weten over de communicatie met anderen nu

72. Communicatie: kwantiteit met anderen (familie, uw vrienden, vreemden)
    * vaak is dat voldoende?
    * soms is dat voldoende?
    * zelden is dat onvoldoende?
    * nooit

73. Communicatie: kwaliteit met anderen
    * hebben anderen het gevoel dat zij "contact" kunnen maken met uw kind?
    * hebben zij het gevoel dat er sprake is van "communicatie": van wederzijds begrip over het "doel" of onderwerp van het contact?
    * zouden zij deze communicatie als "complex" bestempelen of simpel, uiteraard rekening houdend met de leeftijd?
    * hebben zij het gevoel dat er sprake is van een affectieve relatie: van een relatie waarin emoties kenbaar gemaakt kunnen worden?
    * spontaneïteit

74. Communicatie kwaliteit: communicatie breakdowns
    * begrijpen anderen altijd wat uw kind wil zeggen?
        ~moeten zij wel eens om een herhaling vragen?
        ~moet u wel eens vertalen tussen anderen en uw kind?
        ~hoe reageert uw kind hierop?
        ~hoe reageren anderen hierop?
        ~wat doet u hieraan ter preventie
    * begrijpt uw kind altijd wat er gezegd werd?
        ~moet uw kind wel eens om een herhaling vragen?
        ~hoe reageren anderen hierop?
        ~hoe reageert uw kind hierop?
        ~moet u wel eens vertalen tussen anderen en uw kind?
        ~wat doet u hieraan ter preventie
    * "mist" uw kind wel eens informatie?
        ~informele informatie, groepsgesprekken, horende vrienden etc
        ~wat doet u hieraan ter preventie
    * zijn er wel eens zaken die moeilijk zijn over te dragen?
        ~complexe informatie, toekomstige gebeurtenissen etc.
        ~hoe gaan anderen hiermee om

75. Kunnen anderen ook complexere zaken, zoals aangaande het emotionele leven, met uw kind bespreken?
    * vergelijken met andere kinderen

76. Heeft u het gevoel dat ook uw kind dit goed met anderen kan bespreken?
    * vergelijken met andere kinderen

77. Voelen anderen zich wel eens buitengesloten in de communicatie met uw kind als gevolg van gebrekkige communicatie?

Nu zou ik graag wat meer willen weten over de communicatie met vriendjes nu

78. Heeft.....veel vriendjes?
    * doof/horend?

79. Komen deze vriendje ook wel bij jullie thuis/omgekeerd?

80. Communicatie: kwantiteit met vriendjes
    * vaak is dat voldoende?
    * soms is dat voldoende?
    * zelden is dat onvoldoende?
    * nooit

81. Communicatie kwaliteit met anderen is dat voldoende?
    * heeft u het gevoel dat zij "contact" kunnen maken met uw kind?
    * heeft u het gevoel dat er sprake is van "communicatie": van wederzijds begrip over het "doel" of onderwerp van het contact?
    * zou u deze communicatie als "complex" bestempelen of simpel, uiteraard rekening houdend met de leeftijd?
    * heeft u het gevoel dat er sprake is van een affectieve relatie: van een relatie waarin emoties kenbaar gemaakt konden worden?
    * spontaneïteit

82. Communicatie kwaliteit: communicatie breakdowns
    * begrijpen vriendjes altijd wat uw kind wil zeggen?
        ~moeten zij wel eens om een herhaling vragen?
        ~moet u wel eens vertalen tussen vriendjes en uw kind?
        ~hoe reageert uw kind hierop?
        ~hoe reageren vriendjes hierop?
        ~wat doet u hieraan ter preventie
    * begrijpt uw kind altijd wat er gezegd word?
        ~moet uw kind wel eens om een herhaling vragen?
        ~hoe reageren vriendjes hierop?
        ~hoe reageert uw kind hierop?
        ~moet u wel eens vertalen tussen vriendjes en uw kind?
        ~wat doet u hieraan ter preventie
    * "mist" uw kind wel eens informatie?
        ~informele informatie, groepsgesprekken, horende vrienden etc
        ~wat doet u hieraan ter preventie
    * zijn er wel eens zaken die moeilijk zijn over te dragen?
        ~complexe informatie, toekomstige gebeurtenissen etc.
        ~hoe gaan anderen hiermee om

83. Kunnen vriendjes ook complexere zaken, zoals aangaande het emotionele leven, met uw kind bespreken?
    * vergelijken met andere kinderen

84. Heeft u het gevoel dat ook uw kind dit goed met vriendjes kon bespreken?
    * vergelijken met andere kinderen

85. Voelen vriendjes zich wel eens buitengesloten in de communicatie met uw kind als gevolg van gebrekkige communicatie?

Indien oraal:

86. Maakt u zich zorgen over de communicatie van uw kind?

87. Vraagt u zich ooit af of er niet eerder/meer moet worden gebaard?

88. Bent u tevreden over het gevoerde beleid op school?

89. Denkt u dat uw kind op school alléén oraal communiceert
    * verwacht u dat?

91.. Indien thuis-school verschillende communicatievorm
    * conflicten met school?

Indien gebaren:

92. Maakt u zich zorgen over de communicatie van uw kind?

93. Vraagt u zich ooit af of het niet beter zou zijn uw kind meer oraal te stimuleren?

94. Bent u tevreden over het gevoerde beleid op school?

95. Indien thuis-school verschillende communicatievorm
    * conflicten met school?

96. Initiatieven ouders/familie/vrienden ter bevordering communicatie met kind
    * speciaal onderwijs?
    * betrokkenheid bij speciaal onderwijs buitenshuis
    * actieve bijdragen aan taalonderwijs in de thuissituatie
    * gebarentaal of manueel gecodeerde modaliteit geleerd?
        ~ zo ja, goede beheersing? motivatie?
        ~ zo nee, motivatie
    * contacten met andere (ouders van) dove kinderen?

97. Ondersteuning bij opvoeding
    * steun aan elkaar
    * steun aan familie en vrienden

98. Hoe beschrijft u uw kind naar anderen toe?
    * doof, slechthorend, ander

99. Is er gaandeweg (< implant) nog wat veranderd in uw toekomstvisie van uw kind?
    * met betrekking tot communicatie met anderen?
    * met betrekking tot maatschappelijk functioneren?
    * met betrekking op kans op opleiding en carrière?
    * met betrekking op emotionele leven en relatievorming?
        ~relatie met dove, horende, geen verschil

100. Is op enig moment CI als optie ter sprake gekomen?

101. Wat zijn uw afwegingen toen geweest?

102. Hoe ziet u CI?
    * ziet u CI als een middel om een kind horende te maken?
    * ziet u CI als een gereedschap om een doof kind betere kansen in de horen de wereld te geven?
    * ziet u CI als een middel om een kind weerbaarder te maken?
    * ziet u CI als een middel om een tweetalige opvoeding mogelijk te maken?
        ~zo ja, wat is dan in uw mening de eerste taal van het kind?

103. Is de combinatie CI en gebarentaal zinvol denkt u? Waarom?

Politiek

104. Wat vindt u van het woord "doof"?

105. Wat vindt u van het woord "gehandicapt"?

106. Wat vindt u van de maatschappelijke positie van doven in Nederland?

107. Waarbij zouden de doven baat hebben denkt u?

108. Het onderwijsstreven is in toenemende mate op integratie gericht. Wat is hier over uw mening?

109. Bekendheid met opponenten cochleaire implantatie
    * is men thans bekend met het officiële standpunt van Dovenschap?
    * is men thans bekend met het officiële standpunt van de FODOK?
    * is men bekend met de recente oppositionele geschiedenis?
    * is men thans bekend met de achtergronden van deze weerstand?

~ wetenschappelijke/methodologische kritiek
~ ethische/levensbeschouwelijke kritiek
~ emancipatie kritiek
~ politieke kritiek

110. Hoe oordeelt men over deze bezwaren?

111. Wat is nu uw mening over de dovengemeenschap?
* stereotypen?
* angsten?

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CURRICULUM VITAE

Capi Wever (1966) is KNO-arts in opleiding aan het UMC St. Radboud, Nederland's grootste centrum voor cochleaire implantatie bij kinderen. Na de middelbare school (Aruba), studeerde hij "liberal arts" (USA), geneeskunde en filosofie (VU Amsterdam, Groningen, Curaçao). Gedurende zijn studie is hij jarenlang als student-assistent en later als onderzoeker werkzaam geweest aan de vakgroep Filosofie en Medische Ethiek van de Vrije Universiteit. Hij publiceerde in dit kader onder andere, samen met Arko Oderwald, over de ervaring van mensen met een lichamelijke handicap. De auteur is gehuwd met Martine Wever-Koorevaar.

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Het gebaar

Het schilderij “het gebaar ” is in 2002 geschilderd ten behoeve van de omslag van dit proefschrift. Op het schilderij is een kubus te zien die op een ondergrond staat die doet denken aan de vloeren op de schilderijen van Johannes Vermeer. Er ligt een schelp op de kubus. Dit verwijst naar de cochlea van het binnenoor. Drie handen daarboven maken heftige gebaren in de lucht. Deze handen,die zijn ontleend aan het schilderij “de emmaüsgangers ” van Caravaggio, staan voor de discussie tussen voor- en tegenstanders van cochleaire implantatie. Het beeld geeft geen uitsluitsel maar biedt wel mogelijkheden voor interpretatie. Op de voorzijde van de kubus staat een detail uit het schilderij “Oedipus en de sfinx “ van Ingres. Oedipus spreekt niet maar gebaart terwijl hij de sfinx aankijkt met een vragende vasthoudende blik. In de filosofie staat het stellen van de juiste vraag voorop en niet het vinden van een antwoord.
De fluitspeler van Manet gebruikt zijn handen om muziek te maken.
Zijn rechteroor luistert en hij kijkt geconcentreerd in de verte: toekomstmuziek?

Bas Sebus,

“Het gebaar ”, olieverf op doek, 100 x 80 cm

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